



# The Juvenile Onset HD Resource Directory

*Comprehensive Resource Guide  
for Families of Children Affected  
by Juvenile Onset HD*

Information about federal,  
state and local programs



**Huntington's Disease Society of America**



# The Juvenile Onset HD Resource Directory

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who also contributed to this publication



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**Huntington's Disease Society of America**

## **Disclaimer:**

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## About this Guide

Huntington's Disease (HD) is a hereditary brain disorder which leads to multiple physical and mental disabilities that increase over time. In people with the gene that causes HD, symptoms typically begin to appear between the ages of 35 and 45, but the disease may strike those as young as two or as old as 80. Juvenile onset Huntington's Disease (JHD) affects fewer than 10% of all individuals with HD.

JHD often presents different symptoms and challenges than adult onset HD. Ordinary issues of childhood and adolescence are intertwined with the progressive multiple disabilities caused by the disease.

There are programs at the Federal, State and community level which can help families meet the needs of their child or children with JHD. However, finding these programs and getting access to services can be challenging to even the most patient caregiver. Helping families facing JHD locate programs in their region is the goal of this guide.

The Juvenile Onset Huntington's Disease Resource Guide is the result of extensive research and collaboration with social workers, medical professionals and HD families across the country. Our goal is to present as complete a listing of useful resources as possible.

If you have a resource you would like to share, please email HDSA at [Hdsainfo@hdsa.org](mailto:Hdsainfo@hdsa.org) so we can add it to the web based version of this directory.



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## Supplemental Security Income

Supplemental Security Income (SSI) is a federal program of cash assistance to disabled needy individuals of any age, including children. Under SSI, children are considered disabled if they have a physical or mental condition which is so severe that it results in marked and severe functional limitation. The individual's condition must last or be expected to last at least twelve (12) months, or be expected to result in the child's death.

Everyone eligible for Social Security Disability Insurance (SSDI) benefits is also eligible for Medicare after a 24-month qualifying period. The first 24 months of disability benefit entitlement is the waiting period for Medicare coverage. Some states provide an additional cash benefit to individuals receiving SSI.

The exact amount of SSI for which a claimant is entitled depends on what the individual (or the parents in the case of a child) owns and how much income he or she has. Eligibility requirements and benefit payments for federal SSI benefits are identical throughout the 50 states and the District of Columbia. A disability law attorney can also provide state-specific information and guidance in planning for eligibility for SSI benefits.

The HDSA Chapter Social Workers and the Center of Excellence Social Workers are very knowledgeable about the resources in their state and region. Social workers will help you get started with services, and then help with advocacy as needed.

### How does the Social Security Administration define "disabled"?

An individual under age 18 is "disabled" if he or she has a medically determinable physical or mental impairment, which:

- results in marked and severe functional limitations; and
- can be expected to result in death; or
- has lasted or can be expected to last for a continuous period of not less than 12 months.

If the individual is age 18 or older, the disability must also result in the inability to do any substantial gainful activity before benefits are granted.

### What to expect when you apply

When you file an application for SSI benefits based on disability, the agency must first decide whether your family meets the income and resource criteria and other eligibility requirements.

They will ask for:

- Information about your child's physical or mental impairment(s);
- names, addresses, and telephone numbers of doctors, hospitals and any other medical sources he/she has seen;
- Dates of treatment and the kinds of treatment the child has received from doctors, hospitals and other medical sources;
- Names of each prescription and non-prescription medicine that he/she takes and the doctor who prescribed it;
- The kinds of medical tests that have been performed, when and where they were done, and the name of the prescribing physician;
- The name, address, and telephone number of the child's school and teacher.

They will contact doctors, hospitals, schools, teachers, therapists, relatives or others who can provide useful information about your child's impairment(s) and functioning.

If they cannot get enough information from your doctors and other people to decide if your child is disabled, they may arrange and pay for an examination or testing by a qualified medical professional (who may be your own physician, psychologist, optometrist, or speech/language pathologist or other healthcare provider).

### Statements from the child's medical team

In the application for SSI benefits, you will include statements from the child's medical team for the DDS examiners. If possible, have the child examined by an HD specialist, who may be able to make a stronger case based on their expertise. You can find an HD specialist in your area by contacting an HDSA Center of Excellence or your local HDSA Chapter.

The medical team's written statement should include the fact that the child has symptomatic JHD, not just a genetic condition. The statements should be as specific as possible, including the child's diagnosis, a description of the child's disabilities and their prognosis. This is especially important because JHD is a rare disorder and the physicians and examiners at Disability Determination Services (DDS) may not understand its impact on the child.

As you go through the application and appeals process, remain courteous to the people you deal with at Social Security and at the DDS office. They will probably do more for you if you have a friendly relationship. Keep copies of all the child's medical records. Respond promptly to letters and notices and go to any medical exams scheduled by DDS. Do not let important deadlines lapse. If you have questions, calling your local DDS office may be easier and more effective than trying to get through to the Social Security office.

## Medicaid

Medicaid is a jointly funded and administered state and federal welfare program that pays the qualifying medical expenses for those individuals whose financial resources fall below the program's established minimums. Medicaid may pay for such services as hospital and doctor bills not covered by insurance, home healthcare services, medical transportation, and nursing home care.

Medicaid is administered by each state, unlike Medicare, and both are partially funded by the U.S. Centers for Medicare & Medicaid Services (CMS). No two states' Medicaid programs are alike, yet there are certain federally mandated standards common to all Medicaid programs across the nation.

In most states, once a child gets SSI benefits, they can also enroll in Medicaid to help pay medical bills. Many states also have waiver programs under which an individual who is disabled but does not meet the financial criteria may still become eligible for benefits. Eligibility for Medicaid, including home and community-based services waivers, is not determined by the Federal government.

## Medicaid at a Glance

[www.cms.hhs.gov/MedicaidGenInfo/Downloads/MedicaidAtAGlance2005.pdf](http://www.cms.hhs.gov/MedicaidGenInfo/Downloads/MedicaidAtAGlance2005.pdf)

Most recent overview of the Medicaid Program. This 12 page pdf includes:

- Key Eligibility Groups
- Mandatory State Plan Services
- State Chart
- Federal Poverty Guidelines

### Home Care for Children

In some states, children under age 18 who need institutional-level care and live at home may keep Medicaid eligibility while getting home care, if that care is less costly to the government than institutional care. This program is called TEFRA and is also known as the Katie Beckett option. To qualify for TEFRA benefits, the child must be disabled according to the Supplemental Security Income (SSI) definition of disability and must meet the medical-necessity requirement for institutional care. Because there are so few nursing home beds available for children under the age of 16, TEFRA may be an important option for late stage care.

TEFRA is different than Medicaid in that parental income and resources are not considered in awarding benefits. Only the income and resources of the child are counted. Parents may be required to pay a parental fee calculated by using the parents adjusted gross income (before taxes) from last year's tax return and comparing it with the Federal Poverty Guideline.

Children who receive SSI but lose coverage intermittently due to fluctuating parental income may be eligible for TEFRA benefits in the months they do not receive SSI. The child's parent or guardian can apply for TEFRA at the Medicaid office in the child's county of residence.

### State Programs for Children with Special Healthcare Needs

Most states have programs for Children with Special Healthcare Needs. Many of these programs are listed in the Resources by State section of this guide. Among these programs is the Katie Beckett Waiver, also known as the Deeming Waiver of the 2176 Model Waiver. The waiver is part of the Medicaid program and it pays for home-based medical services for children with chronic disabilities whose parents make too much to meet the income requirements of Medicaid. The program is administered by individual states and provisions vary. Ask your primary care physician or medical social worker about additional programs in your state.

### A note on web addresses

Every attempt has been made to provide you with the best possible links to information in this Resource Guide, but website addresses can and do change. If you click on a link or enter a web address and it does not work, don't give up. You can use a search engine, like Google, Yahoo or Ask.com, to find the website. All you need to do is copy the name of the agency or organization (not the old web address) into the search box and you will most likely be taken to the new web address of that organization.



## Federal/National Programs

### Federal Programs

#### Government Benefits

[www.govbenefits.gov](http://www.govbenefits.gov)

GovBenefits.gov is the official benefits website of the U.S. government with information on over 1,000 benefit and assistance programs.

#### Disability Information

[www.disabilityinfo.gov](http://www.disabilityinfo.gov)

Online connection to the federal government's disability-related information and resources, including links on applying for SSI and on state Children's Health Insurance Programs (CHIP).

#### US Department of Health and Human Services – Administration for Children and Families Administration on Developmental Disabilities (ADD)

[www.acf.hhs.gov/programs/add](http://www.acf.hhs.gov/programs/add)

Link to federally funded State Councils on Developmental Disabilities (SCDD) which ensure that individuals with developmental disabilities and their families have access to culturally competent services, supports, and other assistance.

#### Centers for Medicare and Medicaid Services (CMS)

[www.cms.hhs.gov/home/medicaid.asp](http://www.cms.hhs.gov/home/medicaid.asp)

CMS administers the Medicare, Medicaid and the State Children's Health Insurance programs (SCHIP)

#### Benefit Eligibility Screening Tool (BEST)

[http://connections.govbenefits.gov/ssa\\_en.portal](http://connections.govbenefits.gov/ssa_en.portal)

Based on your answers to questions, this tool will list Social Security benefits for which your and/or your child might be eligible and provides information about how to qualify and apply.

#### Center for Mental Health Services (CMHS)

[www.mentalhealth.samhsa.gov/cmhs](http://www.mentalhealth.samhsa.gov/cmhs)

Meeting the mental health needs of children and their families through community-based systems of care. Website provides a state by state services locator.

#### Department of Education (DOE) – Office of Special Education and Rehabilitative Services (OSERS)

[www.ed.gov/about/offices/list/osers/index.html](http://www.ed.gov/about/offices/list/osers/index.html)

OSERS web site includes a wide array of information for families, school districts and states in three main areas: special education, vocational rehabilitation and research.

#### Insure Kids Now

[www.insurekidsnow.gov](http://www.insurekidsnow.gov)

A Children's Health Insurance Program that works to provide free and low-cost health insurance to children under 19. 877-KIDS-NOW connects you to your State program.

#### Social Security Online

[www.socialsecurity.gov/disabilityresearch/wi/medicare.htm](http://www.socialsecurity.gov/disabilityresearch/wi/medicare.htm)

Medicare Information

#### Ticket to Work

[www.ssa.gov/work/receivingbenefits.html](http://www.ssa.gov/work/receivingbenefits.html)

Vocational rehabilitation, training, job referrals, and other ongoing support and services for persons over 18 receiving SSI. Request assistance in job training, locating employers, information about work incentives, etc.

## National Organizations

### The ARC

[www.thearc.org](http://www.thearc.org)

The ARC is the world's largest community-based organization of and for people with intellectual and developmental disabilities. It provides an array of services and support for families and individuals and includes over 140,000 members affiliated through more than 780 state and local chapters across the nation.

### Short Term Assistance and Referral (STAR)

<http://www.arc-anchorage.org/star.htm>

ph 907.777.0113

In many states, ARC offers the STAR Project which provides short term assistance to families of children or adults who experience developmental disabilities.

Some of the ways the STAR Project can help:

- Provide information about programs and/or people who can help
- Help arrange meetings to get services started
- Help with the application process for services through the Division of Senior and Disabilities Services (DSDS), respite programs, SSI, Medicaid, and other assistance programs
- Assist in locating adaptive equipment
- Assist in locating natural supports
- Provide short term respite care if the family is not enrolled in a respite program
- Attend educational and medical meetings when requested by the family
- Assist with behavioral issues
- Listen, problem solve, and plan for the future.

### American Speech-Language-Hearing Association

[www.asha.org/public](http://www.asha.org/public)

Directory of Speech-Language Pathologist and Audiologists

### The Center for Children with Special Needs

[www.cshcn.org](http://www.cshcn.org)

Thoughtful resource for parents of children with chronic health problems in various areas including creating care organizers, finding dental care, child care and the ADA, etc.

### Centers for School Mental Health – Technical Assistance Centers

[www.smhp.psych.ucla.edu](http://www.smhp.psych.ucla.edu)

[www.csmha.umaryland.edu](http://www.csmha.umaryland.edu)

These national training and technical assistance centers focused on mental health in schools were established with partial support from the U.S. Department of Health and Human Services and the Center for Mental Health Services. One center is at UCLA and the other is at the University of Maryland at Baltimore. The web sites include information and resources on school-based mental health programs.

### Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

[www.chadd.org](http://www.chadd.org)

Tips and resources for parents of children with AD/HD.

### Easter Seals

[www.easterseals.com](http://www.easterseals.com)

Services, education, outreach, and advocacy for people with disabilities. Nationwide Directory for the Easter Seals Child Development Center, offering top-quality inclusive care at centers across the country.

### Family Voices

[www.familyvoices.org](http://www.familyvoices.org)

Organization that advocates for family-centered care for all children and youth with special healthcare needs and/or disabilities. Links to individual state organizations.

### IDEA Partnership

[www.ideapartnership.org](http://www.ideapartnership.org)

The IDEA Partnership is dedicated to improving outcomes for students and youth with disabilities by joining state agencies and stakeholders through shared work and learning. The web site includes many helpful resources for schools, families and advocates.

### **Intervention Central**

[www.interventioncentral.org](http://www.interventioncentral.org)

Resources and tools to promote positive classroom behaviors and foster effective learning.

### **The Kaiser Family Foundation**

[www.kff.org/medicaid/index.cfm](http://www.kff.org/medicaid/index.cfm)

Data and information on the Medicaid and CHIP programs by state.

### **National Alliance on Mental Illness**

[www.nami.org](http://www.nami.org)

The NAMI organization operates at the local, state and national levels. Each level of the organization provides support, education, information and referral and advocacy in the area of mental illness. Local programs offer:

- Up-to-date information about medications, side effects, and strategies for medication adherence
- Workshops for problem solving, listening, and communication techniques
- Strategies for handling crises and relapse
- Care for the caregiver: coping with worry, stress, and emotional overload

### **National Assistive Technology Technical Assistance Partnership (ANATTAP)**

[www.resnaprojects.org/nattap/at/statecontacts.html](http://www.resnaprojects.org/nattap/at/statecontacts.html)

Helping individuals remain independent with assistive technology. Links to individual state's assistive technology programs – equipment loans, training, financing, etc.

### **National Information Center for Children and Youth with Disabilities (NICHCY)**

[www.nichcy.org](http://www.nichcy.org)

NICHCY is an information and referral center that provides information on disabilities and disability-related issues (including mental illnesses) for families, educators, and other professionals, with a special focus on children and youth – birth to age 22.

### **Pacer Center**

[www.pacer.org](http://www.pacer.org)

Minnesota-based PACER Center (Parent Advocacy Coalition for Educational Rights) offers excellent publications on schooling and navigating healthcare.

### **ParentsMedGuide.org**

[www.parentsmedguide.org](http://www.parentsmedguide.org)

Guide for medications used in treating children and youth with depression or ADHD.

### **SchoolMentalHealth.org**

[www.schoolmentalhealth.org](http://www.schoolmentalhealth.org)

This site offers school mental health resources not only for clinicians, but also for educators, administrators, parents/caregivers, families, and students. The resources included in the site emphasize practical information and skills based on current research, including prominent evidence based practices, as well as lessons learned from local, state, and national initiatives.

### **School Psychiatry Program and the Mood & Anxiety Disorders Institute (MADI) Resource Center**

[www.schoolpsychiatry.org](http://www.schoolpsychiatry.org)

The School Psychiatry Program and the Mood & Anxiety Disorders Institute (MADI) Resource Center, both part of the Department of Psychiatry at Massachusetts General Hospital (MGH), jointly created Schoolpsychiatry.org. This website is committed to enhancing the education and mental health of every student in every school. The website has resources for parents, educators and clinicians to ensure that each group is working together to support children and teens with mental health conditions.

### **Specialized Training of Military Parents (STOMP)**

[www.stompproject.org](http://www.stompproject.org)

The only National Parent Training and Information Center for military families with special needs children. Offers assistance with issues such as: maintaining continuity of special education programs, finding specialists who take TRICARE, and identifying available state services.



### Technical Assistance Alliance for Parent Centers

[www.taalliance.org](http://www.taalliance.org)

The Technical Assistance Alliance for Parent Centers is an innovative project that supports a unified technical assistance system for the purpose of developing, assisting and coordinating Parent Training and Information Projects and Community Parent Resource Centers under the Individuals with Disabilities Education Act (IDEA).

### Wrightslaw: Special Education Law

[www.wrightslaw.com](http://www.wrightslaw.com)

Website designed for families, advocates, educators, and attorneys looking for accurate, up-to-date information about special education law and advocacy for children with disabilities.

## State and Community Resources

### ALABAMA

#### *State Agencies*

##### Alabama Medicaid Agency

[www.medicaid.state.al.us](http://www.medicaid.state.al.us)

Eligibility and qualifying information, applications and forms.

##### Alabama Department of Education – Special Education

[www.alsde.edu/html/sections/section\\_detail.asp?section=65&footer=sections](http://www.alsde.edu/html/sections/section_detail.asp?section=65&footer=sections)

Documents, forms and checklists about Alabama's special education programs.

##### Alabama Department of Public Health SCHIP

[www.adph.org/allkids](http://www.adph.org/allkids)

Alabama's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

##### Alabama Department of Rehabilitation Services – Children's Rehabilitation Services

[www.rehab.alabama.gov/crs](http://www.rehab.alabama.gov/crs)

Program information on specialty clinical and therapeutic services, care coordination, assistive technology and other services provided to persons with disabilities through 15 community-based offices. Children with neurological conditions are eligible for these services.

##### Alabama Department of Rehabilitation Services – Teen Transition Clinic

[www.rehab.state.al.us/Home/default.aspx?url=/Home/Services/CRS/Programs](http://www.rehab.state.al.us/Home/default.aspx?url=/Home/Services/CRS/Programs)

[Youth+Connection/Teen+Transition+Clinic](#)

Transitional services for youth with special healthcare needs from ages 12-21. A partnership of CRS, Vocational Rehabilitation Service (VRS), State of Alabama Independent Living Service (SAIL) and other community providers.

#### *Community Resources*

##### Alabama Disabilities Advocacy Program (ADAP) – The University of Alabama

[www.adap.net](http://www.adap.net)

Information and referral services and parent trainings on special education topics. Children's Advocacy Team (CHAT) represents individuals in certain cases involving denial of disability services.

##### Alabama Lifespan Respite Resource Network

<http://alabamarespite.org>

Provides respite-related information to families in Alabama, connects families with respite care payment resources, coordinates respite and caregiving trainings, and maintains databases of respite care providers and possible funding resources.

##### Alabama Parent Training & Info Network for Children with Disabilities

[www.alabamaparentcenter.com/ALPTI](http://www.alabamaparentcenter.com/ALPTI)

Information and training for families of children with disabilities to effectively access community and other resources, and understand special education law and dispute resolution.

## ALASKA

### ***State Agencies***

#### **Alaska Public Assistance – Medicaid**

[www.hss.state.ak.us/dpa/programs/medicaid](http://www.hss.state.ak.us/dpa/programs/medicaid)

Eligibility and qualifying information, applications and forms.

#### **Alaska Department of Education & Early Development – Special Education**

[www.eed.state.ak.us/tls/sped/Resources.html](http://www.eed.state.ak.us/tls/sped/Resources.html)

Special Education Handbook, Resources for Parents and Educators and information on understanding the eligibility for Intensive Needs Special Education, among other resources.

#### **Denali Kid Care**

[www.hss.state.ak.us/dhcs/DenaliKidCare](http://www.hss.state.ak.us/dhcs/DenaliKidCare)

Alaska's Children's Health Insurance program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Alaska Health and Social Services – Senior & Disabilities Services – Developmental Disabilities Program**

[www.hss.state.ak.us/dsds/dd/default.htm](http://www.hss.state.ak.us/dsds/dd/default.htm)

Information on Alaska's programs for children with disabilities, including Special Education, Home and Community-based Waiver Services for Children with Complex Medical Conditions, and Developmental Disabilities eligibility.

#### **Alaska Department of Education & Early Development – Mediation, Complaints & Due Process**

[www.eed.state.ak.us/tls/sped/Mediation.html#aksystem](http://www.eed.state.ak.us/tls/sped/Mediation.html#aksystem)

State mediation system for disputes between parents and a district that they are unable to resolve.

#### **Alaska Health and Human Services – Office of Children's Services – Residential Care**

[www.hss.state.ak.us/ocs/ResidentialCare/default.htm](http://www.hss.state.ak.us/ocs/ResidentialCare/default.htm)

Mental Health Residential Care for Children & Youth. Short-term emergency shelter and long-term residential treatment.

### ***Community Resources***

#### **Stone Soup Group**

[www.stonesoupgroup.org](http://www.stonesoupgroup.org)

Parent Training and Information Project that offers assistance in obtaining services, liaison assistance between clinics, the family and the child's medical home, referrals to community and other services.

## **ARIZONA**

### ***State Agencies***

#### **Arizona Healthcare Cost Containment System – Medicaid**

[www.azahcccs.gov](http://www.azahcccs.gov)

Eligibility and qualifying information, applications and forms.

#### **Arizona Department of Education – Exceptional Student Services**

<http://www.ade.az.gov/ess/specialprojects/pinspals>

Parent Information Network of specialists who provide on-site and phone consultation, training, resources, and information and referrals to support parents of special education students. Links to booklets and other information.

#### **Kids Care**

[www.kidscare.state.az.us](http://www.kidscare.state.az.us)

Arizona's Children's Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

#### **Arizona Department of Economic Security – Division of Developmental Disabilities**

<https://egov.azdes.gov/cmsinternet/main.aspx?menu=96&id=2454>

Information and eligibility requirements for services to persons with disabilities.

#### **Arizona Department of Health Services – Public Health Prevention Services – Office for Children with Special Care Needs**

<http://www.azdhs.gov/phs/ocshcn>

Gateway to Children's Rehabilitative Services, Medical Home Coordinated Healthcare Services, Parent to Parent Support, Advocacy and Protection and other state agencies and programs for children with disabilities.

#### **First Call for Help – Community Information and Referral**

<http://www.cir.org>

Database of local resources from nonprofit and government agencies in Arizona.

### ***Community Resources***

#### **Raising Special Kids**

<http://www.raisingpecialkids.org/services/programs.aspx>

Parent Training and Information Network providing training, resources, and support to families of children with disabilities and special healthcare needs in Arizona. Parent to parent support and assistance with special education issues and transition services.

#### **Pilot Parents of Southern Arizona**

[www.pilotparents.org](http://www.pilotparents.org)

Parent Training and Information Center serving Cochise, Gila, Graham, Greenlee, La Paz, Pima, Pinal, Santa Cruz and Yuma counties. Provides resources, training and support to families of children with disabilities. Parent to Parent assistance with the special education process, etc.

## **ARKANSAS**

### ***State Agencies***

#### **Arkansas Medicaid**

[www.medicaid.state.ar.us](http://www.medicaid.state.ar.us)

Eligibility and qualifying information, applications and forms.

#### **Arkansas Department of Education – Special Education – Direct Services Support**

[arksped.k12.ar.us/sections/dss.html](http://arksped.k12.ar.us/sections/dss.html)

Information on Arkansas' special education programs. Links to key resources.

#### **ARKids First**

[www.arkidsfirst.com/home.htm](http://www.arkidsfirst.com/home.htm)

Arkansas' Children's Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

#### **Arkansas Department of Human Services**

[www.arkansas.gov/dhs/homepage.html](http://www.arkansas.gov/dhs/homepage.html)

Service directory of Medicaid and mental health services, services for persons with developmental disabilities, respite care services, and more.

#### **Arkansas Department of Human Services – Division of Developmental Disabilities Services**

[www.arkansas.gov/dhs/ddds/NewWebsite](http://www.arkansas.gov/dhs/ddds/NewWebsite)

Information on Arkansas' community-based services, waiver services, application directions and guides to Services for Children with Disabilities.

#### **Arkansas Department of Human Services – Division of Behavioral Health Services**

[www.arkansas.gov/dhs/dmhs](http://www.arkansas.gov/dhs/dmhs)

Community-based mental health services provided statewide through 15 private, non-profit community mental health centers (CMHCs), their affiliates, and three mental health clinics.

#### **Disability Rights Center – Client Assistance Program**

[www.arkdisabilityrights.org/cap.html](http://www.arkdisabilityrights.org/cap.html)

Information, education and referrals to assist disabled persons receiving or seeking services. Individual advocacy is available in special instances.

### ***Community Resources***

#### **Arkansas Disability Coalition**

<http://www.adcpti.org>

Parent Training and Information Center that teaches parents of children ages 0-26, with special education needs, how to develop and monitor effective educational plans for their children.

#### **Arkansas Support Network**

[www.supports.org](http://www.supports.org)

Parent Training and Information Center that assists parents in obtaining community living services, supported living, personal care, supported employment and other services for their children with disabilities.

#### **FOCUS, Inc.**

[www.focusinonline.org](http://www.focusinonline.org)

Parent Training and Information Center that assists parent in advocating for their children with disabilities in the special education process and provides Medicaid Waiver services such as case management and direct care.

## **CALIFORNIA**

### ***State Agencies***

#### **California Department of Healthcare Services – Medi-Cal**

[www.medi-cal.ca.gov](http://www.medi-cal.ca.gov)

Eligibility and qualifying information, applications and forms.

#### **California Department of Education/Special Education – Family Involvement and Partnerships**

[www.cde.ca.gov/sp/se/fp](http://www.cde.ca.gov/sp/se/fp)

Information, resources and support for parents, guardians and families of children with disabilities.

#### **California Healthy Families Program**

[www.healthyfamilies.ca.gov](http://www.healthyfamilies.ca.gov)

California's Children's Health Insurance Program (CHIP) which offers affordable insurance for children and teens not eligible for Medicaid.

#### **Department of Disability Services**

[www.dds.ca.gov/EarlyStart/Home.cfm](http://www.dds.ca.gov/EarlyStart/Home.cfm)

Healthcare providers, early intervention specialists, therapists, and parent resource specialists for young children with disabilities.

#### **California Department of Healthcare Services**

##### **California Children's Services (CCS)**

[www.dhcs.ca.gov/services/ccs/Pages/default.aspx](http://www.dhcs.ca.gov/services/ccs/Pages/default.aspx)

Gateway to the state program for children, up to age 21, with special healthcare needs, including children with diseases of the nervous system.

#### **California Department of Mental Health – Programs for Children and Youth**

[www.dmh.ca.gov/default.asp](http://www.dmh.ca.gov/default.asp)

Services for children and youth directly provided at the local level by counties and their contract providers. Directory of county mental health agencies. Eligibility, applications and links to county offices.

### ***Community Resources***

#### **Chinese Parents Association for the Disabled**

[www.cpad.org](http://www.cpad.org)

In Anaheim, providing support and assistance with special education issues.

#### **Fiesta Educativa**

[www.fiestaeducativa.org](http://www.fiestaeducativa.org)

Community Parent Resource Centers (CPRC) for parents of children with disabilities in the Latino and Chinese communities with links to Regional Committees.

#### **Matrix Parent Network and Resources Center**

[www.matrixparents.org](http://www.matrixparents.org)

Based in Marin, Napa, Solano and Sonoma counties, Matrix is a parent-run information and resource center providing no-cost information, education and emotional support services to families of children with special needs (birth through age 26).

#### **Parents Helping Parents**

[www.php.com/specialed](http://www.php.com/specialed)

PHP provides a wide range of services to help parents better understand, support and advocate for their children in special education programs.

#### **Rowell Family Empowerment of Northern California, Inc.**

[www.rfenc.org/respite.php](http://www.rfenc.org/respite.php)

In Shasta, Butte and Tehama counties, PFENC offers no-charge respite services to families who have a child, ages 0-18 with a disability, who is a client of Far Northern Regional Center.

**Support for Families of Children with Disabilities**

[www.supportforfamilies.org/family\\_links.html](http://www.supportforfamilies.org/family_links.html)

In San Francisco, SFGCD assists families in accessing the mental health system.

**Team of Advocates for Special Kids (TASK)**

[www.taskca.org](http://www.taskca.org)

In Anaheim, Long Beach and San Diego, TASK is a federally-funded Parent Training and Information Center, serving children 0-26. Special Education advocates offer one-to-one assistance over the telephone and answer questions for parents and professionals concerning their child's or client's rights.

**Vietnamese Parents with Disabled Children Association, Inc. (VPDCA)**

[www.vpdca.org](http://www.vpdca.org)

Providing support and assistance with special education issues in Carson, CA.

## COLORADO

### *State Agencies*

Colorado Dept. of Healthcare Policy and Financing – Medicaid  
[www.colorado.gov/cs/Satellite/HCPF/HCPF/1197364086675](http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1197364086675)

Medicaid and Child Health Plan Plus programs as well as a variety of other programs for Colorado’s low-income families, the elderly and persons with disabilities.

Colorado Department of Education – Exceptional Student Leadership Unit (CDE – ESLU)  
[www.cde.state.co.us/index\\_special.htm](http://www.cde.state.co.us/index_special.htm)

Resources on Colorado’s Special Education programs and information on educational specialists, parent-professional partnerships and more.

Colorado Child Health Plan Plus  
[www.cchp.org](http://www.cchp.org)

Colorado’s Children’s Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

Colorado Department of Human Services  
[www.cdhs.state.co.us](http://www.cdhs.state.co.us)

Directory of Colorado’s 64 county departments for social/human services, public mental health system, and services for people with developmental disabilities.

Colorado Department of Human Services – Division for Developmental Disabilities (DDD) and Community Centered Boards (CCBs)

[www.cdhs.state.co.us/ddd](http://www.cdhs.state.co.us/ddd)

Information hub for Colorado’s developmental disability services. Eligibility, information for individuals and families, FAQs, and links to the individual Community Centered Boards which administer services.

Colorado Department of Human Services – Disability Determination Services (DDS)  
[www.cdhs.state.co.us/dds](http://www.cdhs.state.co.us/dds)

Eligibility rules and procedures of the state agency that makes disability determinations for Social Security.

Colorado Department of Public Health and Environment – Children with Special Healthcare Needs Unit

[www.cdphe.state.co.us/ps/hcp/home/respice.html](http://www.cdphe.state.co.us/ps/hcp/home/respice.html)

Program for children and teens with Special Healthcare Needs that can evaluate your family’s needs, talk to you about medical care, services, insurance and more. A source for short term respite care.

### *Community Resources*

Assistive Technology Partners  
[uchsc.edu/atp](http://uchsc.edu/atp)

Assistance through the University of Colorado Denver with obtaining assistive technology: wheelchairs, communication devices, computers, electronic aids to daily living, and learning/cognitive aids.

CCA: Colorado Citizens for Accountability  
[www.coloradocitizensforaccountability.org](http://www.coloradocitizensforaccountability.org)

- Information on guardianship and durable power of attorney
- Advocacy training for those who have family members in the hospital
- Support for families/individuals dealing with legal issues in the medical system

PEAK: Colorado’s Parent Training and Information Center  
[www.peakparent.org](http://www.peakparent.org)

PEAK Parent Center, the Colorado Department of Education, and the Colorado Developmental Disabilities Council provide person-centered special educational planning assistance to people with disabilities between the ages 3-30 years old. Low or no-cost services.



## **CONNECTICUT**

### ***State Agencies***

**Connecticut Department of Social Services – Medicaid**  
[www.ct.gov/dss/cwp/view.asp?a=2353&q=305218#MAID](http://www.ct.gov/dss/cwp/view.asp?a=2353&q=305218#MAID)

Information hub for Connecticut's healthcare programs, including Medicaid. Link to Medicaid brochure.

**Connecticut State Department of Education: Special Education**  
[www.sde.ct.gov/sde/cwp/view.asp?a=2678&Q=320730](http://www.sde.ct.gov/sde/cwp/view.asp?a=2678&Q=320730)

Links to special education resources, including IEP forms and useful links outside the agency.

**Connecticut Husky Healthcare for Uninsured Children and Youth**  
[www.huskyhealth.com](http://www.huskyhealth.com)

Connecticut's Children's Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

**Connecticut Department of Developmental Services (DDS)**  
[www.ct.gov/dds](http://www.ct.gov/dds)

Eligibility and application information for services to persons with developmental disabilities, including case management, family support services, respite, etc.

**Connecticut Medical Home Initiative for Children & Youth with Special Healthcare Needs (CYSHCN)**

[www.ct.gov/dph/cwp/view.asp?a=3138&q=387702](http://www.ct.gov/dph/cwp/view.asp?a=3138&q=387702)

Information on Connecticut's Medical Home program for children with disabilities, in which a pediatric healthcare professional works in partnership with the family to access and coordinate special care, educational services, out-of-home care, family support, respite and other public and private community services.

**Connecticut Department of Social Services – ConnPACE**  
[www.connpace.com](http://www.connpace.com)

Links to multiple programs that provide assistance with prescription costs to individuals with disabilities.

**Connecticut Department of Mental Health and Addiction Services**  
[www.ct.gov/dmhas](http://www.ct.gov/dmhas)

Service locator and links to 24-hr crisis services.

### ***Community Resources***

**Connecticut Parent Advocacy Center (CPAC)**  
[www.cpacinc.org](http://www.cpacinc.org)

Parent advocates offering information and support to families of children with any disability or chronic illness, age birth through 26.

**Disabilities Network of Eastern Connecticut**  
[www.dnec.org](http://www.dnec.org)

Advocacy services for individuals with disabilities who are having difficulty obtaining benefits, social services, access to public facilities, or when discrimination is taking place in employment, education, or communication.

## DELAWARE

### *State Agencies*

Delaware Health and Social Services – Medicaid

[www.dhss.delaware.gov/dss/medicaid.html](http://www.dhss.delaware.gov/dss/medicaid.html)

Eligibility and qualifying information, applications and forms.

Delaware Department of Education: Special Education

<http://www.doe.state.de.us/programs/specialed>

Links to special education services.

Delaware Healthy Children Program

[www.state.de.us/dhss/dss](http://www.state.de.us/dhss/dss)

Delaware's Children's Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

Delaware Health and Social Services – Division of Developmental Disabilities Services

[www.state.de.us/dhss/ddd/index.html](http://www.state.de.us/dhss/ddd/index.html)

Information on applying for services, including family support, case management, medical services, respite, etc.

Delaware Division of Child Mental Health Services

<http://kids.delaware.gov/cmhs/cmhs.shtml>

Accessible, effective behavioral health treatment services for children in collaboration with families and service partners.

### *Community Resources*

Delaware Assistive Technology Initiative

[www.dati.org](http://www.dati.org)

Program to make assistive technology available at no or low cost, including equipment recycling.

Parent Information Center of Delaware (PIC)

[www.picofdel.org](http://www.picofdel.org)

Parent Information and Training Center providing support and information to parents of children with disabilities. Parent to parent consulting on special education topics, seminars and training, and online resource center.

## DISTRICT OF COLUMBIA

### *State Agencies*

#### District of Columbia Department of Health – Medicaid and DC Healthy Families Insurance Program

[www.dhcf.dc.gov](http://www.dhcf.dc.gov)

Links to Medicaid and DC Healthy Families Insurance programs (SCHIP) which offers affordable healthcare for children and teens not eligible for Medicaid.

#### District of Columbia Public Schools – Office of Special Education

[www.k12.dc.us/offices/ose/index.htm](http://www.k12.dc.us/offices/ose/index.htm)

Information on the District's special education programs and policies.

#### District of Columbia Department on Disability Services

[www.dds.dc.gov/dds/site/default.asp](http://www.dds.dc.gov/dds/site/default.asp)

Website under construction. Promises information regarding applying for services, how to find qualified providers and other key resources.

#### District of Columbia Health Services for Children with Special Needs, Inc.

[www.hscsn-net.org](http://www.hscsn-net.org)

Innovative care management network coordinating health, social, and education services for the pediatric Supplemental Security Income (SSI) and SSI-eligible populations of Washington, DC.

#### District of Columbia Department of Mental Health – Access Helpline

[www.dmh.dc.gov/dmh/cwp/view,A,3,Q,515987,dmhNav,\[31250\].asp](http://www.dmh.dc.gov/dmh/cwp/view,A,3,Q,515987,dmhNav,[31250].asp)

Overview of the DC Mental Health Access Helpline (1-888-793-4357), which is a 24-hour a day telephone service for emergency or ongoing mental healthcare services for children, youth and adults.

### *Community Resources*

#### Advocates for Justice and Education, Inc.

[www.AJE-DC.org](http://www.AJE-DC.org)

Parent Training and Information Center that offers Parent to Parent support network. Provides professional individual representation in situations when the intervention of a third party is necessary to ensure that appropriate services are being made available to children with disabilities.

#### HSC (Health Services for Children) Pediatric Center

[www.hscpediatriccenter.org](http://www.hscpediatriccenter.org)

Hospital assisting children to adapt to lifelong issues related to chronic illness or their disabilities. Provides a link to HSC Foundation's Community Services Resource Directory of healthcare and social services providers, government agencies, nonprofit organizations, and advocates for community services throughout the District of Columbia.

## FLORIDA

### *State Agencies*

#### Florida Department of Children and Families – Medicaid

[www.dcf.state.fl.us/ess](http://www.dcf.state.fl.us/ess)

Access to Florida's system of information about benefits and eligibility for Medicaid and other public assistance programs.

#### Florida Department of Education – Exceptional Education and Student Services

[www.fl DOE.org/ese/ese-home.asp](http://www.fl DOE.org/ese/ese-home.asp)

Basic information on state programs and the responsibilities of school districts.

#### Healthy Kids

[www.healthykids.org](http://www.healthykids.org)

Florida's Children's Health Insurance Program (CHIP) which offers affordable healthcare for children and teens not eligible for Medicaid. Includes dental benefits.

#### State of Florida – Agency for Persons with Disabilities

[www.apd.myflorida.com/customers](http://www.apd.myflorida.com/customers)

Information on new 4-tier waiver program for person with disabilities. Links to brochures and applications.

#### Florida Department of Health – Children's Medical Services (CMS)

<http://www.cms-kids.com>

Medical, therapeutic and supportive services to children with special healthcare needs who are eligible for Medicaid, KidCare or CMS Network Safety Net. Eligibility rules, benefits and other information.

#### Florida Department of Children and Families – Mental Health

[www.dcf.state.fl.us/mentalhealth](http://www.dcf.state.fl.us/mentalhealth)

Mental healthcare resources for children and adults. Links to the 15 district offices.

### *Community Resources*

#### Central Florida Parent Center, Inc.

[www.cflparents.org](http://www.cflparents.org)

Parent Training and Information Center that assists parents of children with disabilities and young adults with disabilities to cooperatively and effectively participate in planning and decision-making related to early intervention, educational, and transitional services under IDEA.

#### Florida Alliance for Assistive Service and Technology

<http://faast.org>

Statewide loan program for assistive technology devices which allows individuals to try out and train on devices. Includes classified ads to buy, sell or trade assistive technology. Includes eligibility requirements.

#### Family Network on Disabilities of Florida

[www.fndfl.org/Programs.asp](http://www.fndfl.org/Programs.asp)

Links to local programs throughout the state. Parent Training and Information Centers, transition services and parent to parent support.

## **GEORGIA**

### ***State Agencies***

Georgia Department of Human Services, Division of Family and Children Services – Medicaid  
<http://dfcs.dhr.georgia.gov/portal/site/DHR-DFCS>

State Medicaid program, accessed through Services menu, with application information and list of county offices.

Georgia Department of Education – Division for Exceptional Students  
[www.gadoe.org/ci\\_exceptional.aspx](http://www.gadoe.org/ci_exceptional.aspx)

Services and support information on Georgia's special education programs.

PeachCare for Kids  
[www.peachcare.org](http://www.peachcare.org)

Georgia's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Georgia Department of Community Health – Children's Medical Services.  
[www.health.state.ga.us/programs/specialneeds/index.asp](http://www.health.state.ga.us/programs/specialneeds/index.asp)

Coordinated system of medical/healthcare for eligible children, birth to 21, with chronic medical conditions, provided through a network of 21 district offices at low or no cost, depending on eligibility.

Georgia Department of Behavioral Health and Developmental Disabilities  
[www.dbhdd.georgia.gov/portal/site/DBHDD](http://www.dbhdd.georgia.gov/portal/site/DBHDD)

Links to Developmental Disabilities programs and services, regional office locator and information on waiver programs.

Georgia Department of Human Resources – Behavioral Health Link  
[www.mygcal.com](http://www.mygcal.com)

24-hour Crisis and Access Line, plus Resource Base with local resources for children and adults with mental health and developmental disabilities.

Georgia Department of Labor – Vocational Rehabilitation Program – Disability Adjudication Services

[www.vocrehabga.org/dasfacts.html](http://www.vocrehabga.org/dasfacts.html)

Information on the program that determines disability for the purpose of SSI eligibility.

### ***Community Resources***

Fragile Kids Foundation  
[www.fragilekids.org](http://www.fragilekids.org)

Foundation that provides loans and grants of equipment for Georgia's medically fragile children. Equipment may include a wheelchair lift installed in a family's van, toileting systems, lifting systems, bath chairs and specialized car seats.

Georgia Advocacy Office, Inc.  
<http://www.thegao.org>

Private not-for-profit corporation that offers assistance to persons with disabilities to obtain special education services; also delivers parent training programs and locates funding for assistive technology.

Georgia Assistive Technology Act Program – Tools for Life  
[www.gatfl.org](http://www.gatfl.org)

Demonstrations, trainings and help with obtaining assistive technology. Extensive links to internet resources.

Georgia Children's Network (GCN)  
<http://groups.yahoo.com/group/GA-ChildrensNetwork>

Online discussion group in GA bringing parents and grandparents of special needs children together with other parents, advocates, professionals, service providers and community organizations

Parent to Parent of Georgia, Inc.  
[www.parenttoparentofga.org](http://www.parenttoparentofga.org)

Support and information for parents of children with disabilities. Parent to parent support available. "Roadmap to Services" contains hundreds of web pages with a wealth of information on many topics of interest to families.

## HAWAII

### ***State Agencies***

#### **Hawai'i Department of Human Services – QUEST Hawai'i** [www.med-quest.us](http://www.med-quest.us)

Eligibility and qualifying information for Med-QUEST, which includes Medicaid and the Hawai'i children's health insurance program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Hawai'i Department of Education – Special Education** [www.doe.k12.hi.us/specialeducation/index.htm](http://www.doe.k12.hi.us/specialeducation/index.htm)

Overview information on Hawai'i's special education programs, student's rights, mediation procedures, etc.

#### **Hawai'i Department of Health – Developmental Disabilities Division** [www.cmisb.org/default.asp](http://www.cmisb.org/default.asp)

Application and eligibility information on home and community-based services, including family support services, chore and personal assistance, skilled nursing, respite care, etc.

#### **Hawai'i Department of Health – Children with Special Health Needs Branch** <http://hawaii.gov/health/family-child-health/cshcn/index.html>

Care coordination, nursing and social work for low-income children ages 0-21 with disabilities. Some limited financial help with medical services.

#### **Hawai'i Department of Health – Children and Adolescent Mental Health Division (CAMHD)** [www.hawaii.gov/health](http://www.hawaii.gov/health)

Mental health services for children and youth accessed through Family Guidance Centers. Both school-based services and more intensive mental health services available.

### ***Community Resources***

#### **Assistive Technology Resource Centers of Hawai'i (ATRC)** [www.atrc.org](http://www.atrc.org)

ATRC utilizes demonstrations, outreach, technical assistance, public awareness, device loans and trials, financial lending and other programs to help match individuals with disabilities to assistive technologies. Offers a classified ad system for buying, selling and trading assistive technology devices.

#### **Learning Disabilities Association of Hawai'i** [www.ldahawaii.org](http://www.ldahawaii.org)

Educational advocacy, training, support and other programs for children with disabilities. Offers PIN grants for speech-language pathology.

#### **Special Parent Information Network (SPIN)** [www.spinhawaii.org](http://www.spinhawaii.org)

Parent Training and Information Center that provides information, support and referral to parents of children and young adults with disabilities, including special education advocacy, community resources, etc.

## IDAHO

### *State Agencies*

#### Department of Health and Welfare – Medical Services

[www.healthandwelfare.idaho.gov/Medical/tabid/61/Default.aspx](http://www.healthandwelfare.idaho.gov/Medical/tabid/61/Default.aspx)

Medicaid and Children's Health Insurance Program eligibility and qualifying information, applications and forms.

#### Idaho Department of Education – Special Education

[www.sde.idaho.gov/site/special\\_edu](http://www.sde.idaho.gov/site/special_edu)

Information on Idaho's special education programs, with links to the special education manual, Medicaid consent forms for school based services and dispute resolution.

#### Idaho Department of Health and Welfare – Idaho Health Plan Coverage

<http://www.healthandwelfare.idaho.gov/?TabId=219>

Idaho's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### Idaho Department of Health and Welfare – Developmental Disabilities

[healthandwelfare.idaho.gov/Medical/DevelopmentalDisabilities/tabid/120/Default.aspx](http://healthandwelfare.idaho.gov/Medical/DevelopmentalDisabilities/tabid/120/Default.aspx)

Information on Idaho's programs for person with developmental disabilities, including family support programs, and service coordination.

#### Idaho Department of Health and Welfare – Children's Services

[www.healthandwelfare.idaho.gov/Children/tabid/57/Default.aspx](http://www.healthandwelfare.idaho.gov/Children/tabid/57/Default.aspx)

Links to Medicaid, Children's Special Health Needs and Children's Mental Health services, FAQs, and links to regional offices.

#### Idaho Department of Health and Welfare – Children's Special Health Program

[www.csdp.dhw.idaho.gov](http://www.csdp.dhw.idaho.gov)

Consultation, information, technical assistance and referral services for the families of uninsured children who have chronic illnesses and disabilities.

### *Community Resources*

#### Idaho Assistive Technology Project

[www.idahoat.org](http://www.idahoat.org)

Assistance in obtaining assistive technology, a used equipment exchange, an alternative financing program, assistive technology support for schools, and training events throughout Idaho.

#### Children's Disabilities Information

[www.childrensdisabilities.info](http://www.childrensdisabilities.info)

Articles and resources including links to special needs stores, animal therapy opportunities, parent groups, etc.

#### Idaho Help Family Support 360 Project

<http://www.idahocdh.org/dnn/idhelp/Default.aspx>

Statewide community resource directory from the University of Idaho, Center on Disabilities and Human Development.

#### Idaho Parents Unlimited, Inc. (IPUL)

[www.ipulidaho.org](http://www.ipulidaho.org)

Information hub for families of children with disabilities dedicated to promoting family-centered care. Includes links to the Idaho Parent Training and Information Center (PTI), where Parent Education Coordinators offer expertise on navigating disability services, agencies, and programs; Family 2 Family information and resource program; and the VSA Arts of Idaho.

## ILLINOIS

### ***State Agencies***

#### **Illinois Department of Health and Family Services – Medicaid**

[www.hfs.illinois.gov/programs](http://www.hfs.illinois.gov/programs)

Eligibility and qualifying information, applications and forms.

#### **Illinois State Board of Education: Special Education Services**

<http://www.isbe.net/spec-ed>

Links to programs, definitions, publications, trainings and forms.

#### **Illinois Department of Healthcare and Family Services – Illinois All Kids**

[www.allkids.com](http://www.allkids.com)

Illinois's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Illinois Department of Human Services**

[www.dhs.state.il.us](http://www.dhs.state.il.us)

Information hub with links to Developmental Disability, Disability and Rehabilitation, Disability Determination, Vocational Rehabilitation, Mental Health and Home Services Programs, among others.

#### **Department of Human Services – Disability Determination Services**

<http://www.dhs.state.il.us/page.aspx?item=29979>

Agency responsible for determining eligibility for SSI.

### ***Community Resources***

#### **University of Illinois at Chicago – Division of Specialized Care for Children (DSCC)**

<http://www.ahs.uic.edu/dhd>

Information and referrals to community resources offering care coordination, home care, Children's Habilitation Clinic, etc. through 13 regional offices throughout the state.

#### **Equip for Equality, Inc.**

<http://www.equipforequality.org>

Statewide, cross-disability, comprehensive advocacy organization providing self-advocacy assistance, legal services, and disability rights education.

#### **Family Matters – Parent Training and Information Center**

<http://www.fmptic.org>

Information and trainings for parents about special education services for school aged children. Assistance with transition issues for students who will be leaving the educational system.

#### **Family Resource Center on Disabilities**

<http://www.frcd.org>

Information and training on Special Education Rights and due process, serving the 8 counties around Chicago.

#### **Family Support Network of Illinois**

<http://www.familysupportnetwork.org>

Information about home-based support services that help disabled individuals live at home and how to apply for them.

#### **Project CHOICES**

[www.projectchoices.org](http://www.projectchoices.org)

Illinois State Board of Education initiative that partners with local school districts to provide access for all students through general education. Offers ideas and tools for greater inclusion in general education classes.



## INDIANA

### *State Agencies*

Indiana Family & Social Services Administration – Office of Medicaid Policy and Planning – Medicaid

[www.in.gov/fssa/2408.htm](http://www.in.gov/fssa/2408.htm)

Information hub on Indiana's Medicaid program, Medicaid waiver programs, and Children's Health Insurance Program.

Indiana Department of Education – Special Education

[www.doe.in.gov/exceptional/speced/welcome.html](http://www.doe.in.gov/exceptional/speced/welcome.html)

Information hub for Indiana's Special Education programs with links to rules, monitoring, due process, etc.

Indiana Family and Social Services Administration – Hoosier Healthwise – Children's Health Insurance Program

[www.healthcareforhoosiers.com](http://www.healthcareforhoosiers.com)

Indiana's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Indiana Family and Social Services Administration – Division of Disability and Rehabilitative Services

[www.in.gov/fssa/2328.htm](http://www.in.gov/fssa/2328.htm)

Services for people with disabilities, provided through 8 regional offices that include caregiver support, home and community-based Medicaid waivers, assistive technology, transition services and supported employment.

Indiana Department of Health – Children's Special Healthcare Services (CSHCS)

[www.in.gov/isdh/19613.htm](http://www.in.gov/isdh/19613.htm)

Provides supplemental medical coverage to help families of children who have serious, chronic medical conditions, ages birth to 21, who meet the program's financial and medical criteria.

Indiana Family and Social Services Administration – Division of Mental Health and Addiction

[www.IN.gov/fssa](http://www.IN.gov/fssa)

Information hub for Indiana's mental health services for children and adults.

Indiana Protection and Advocacy Services

[www.in.gov/ipas](http://www.in.gov/ipas)

Agency that assists families to secure appropriate medical, psychiatric or rehabilitation services for their children with disabilities and to assist in securing free and appropriate public education services for children with disabilities.

### *Community Resources*

About Special Kids, Inc. (ASK), formerly the Indiana Parent Information Network, Inc. (IPIN)

[www.aboutspecialkids.org](http://www.aboutspecialkids.org)

A "Parent to Parent" organization that works throughout the state of Indiana to answer questions and provide support, as well as information on the various systems related to special needs.

Indiana Resource Center for Families with Special Needs – IN\*SOURCE

[www.insource.org](http://www.insource.org)

Parent Training and Information Center, parent to parent mentoring and other programs to educate parents on special education processes and other disability topics.

Indiana Institute on Disability and Community – Center for Disability Information and Referral

[www.iidc.indiana.edu/index.php?pageId=34](http://www.iidc.indiana.edu/index.php?pageId=34)

Information and resources for people with disabilities, their families and professionals.

## IOWA

### ***State Agencies***

#### **Iowa Medicaid Enterprise**

[www.ime.state.ia.us](http://www.ime.state.ia.us)

Information hub for the Iowa Medicaid program, including the Medically Needy program, which offers partial payment for medical services to higher income families who apply through their local DHS office.

#### **Iowa Department of Education – Special Education**

[www.state.ia.us/educate](http://www.state.ia.us/educate)

Information hub for Iowa's Special Education programs and services including links to Parent Information, Conflict Resolution, etc.

#### **Hawk-I**

[www.hawk-i.org](http://www.hawk-i.org)

Iowa's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Iowa Department of Human Rights – Division of Persons with Disabilities**

[www.state.ia.us/government/dhr/pd/index.html](http://www.state.ia.us/government/dhr/pd/index.html)

Iowa Client Assistance Program (ICAP) offers assistance to individuals seeking or receiving services from the Division of Vocational Rehabilitation Services, Projects with Industry, or Independent Living Programs.

#### **Iowa Department of Human Services – Home and Community-Based Services**

[www.ime.state.ia.us/HCBS/HCBSindex.html](http://www.ime.state.ia.us/HCBS/HCBSindex.html)

Link to Medicaid page and interactive map of local DHS offices where one applies for services.

#### **Iowa Vocational Rehabilitation Services**

[www.ivrs.iowa.gov](http://www.ivrs.iowa.gov)

Agency that administers the Disability Determination Services Bureau (DDS) and the Rehabilitation Services Bureau. DDS determines eligibility for SSI.

### ***Community Resources***

#### **Access for Special Kids Family Resource Center (ASK)**

[www.askresource.org](http://www.askresource.org)

ASK Resource Center provides a broad range of information and advocacy including parent to parent coaching, healthcare coordination, and referrals to community-based services.

#### **Iowa COMPASS**

[www.iowacompass.org](http://www.iowacompass.org)

Iowa COMPASS is Iowa's free, statewide information and referral service for people with disabilities, their families, service providers, and other members of the community. Offers trainings in disability awareness and classified ads for used assistive technology.

#### **Iowa Program for Assistive Technology (IPAT)**

[www.uiowa.edu/infotech](http://www.uiowa.edu/infotech)

IPAT operates an information and referral service for assistive technology called InfoTech to help callers find resources for new and used assistive technology and funding.

#### **Iowa Protection and Advocacy Services, Inc.**

[www.ipna.org](http://www.ipna.org)

Specialized team of disability advocates knowledgeable in training parent advocates and obtaining services in special education.

## KANSAS

### *State Agencies*

#### **Kansas Medical Assistance Program – Medicaid**

[www.kmap-state-ks.us](http://www.kmap-state-ks.us)

Overview of the Kansas Medicaid program, eligibility rules and enrollment assistance.

#### **Kansas State Department of Education – Special Education Services**

<http://www.ksde.org/Default.aspx?tabid=101>

Information hub for Kansas' Special Education Programs, including a link to the Parents Guide to Special Education.

#### **Kansas HealthWave**

[www.kansashealthwave.org](http://www.kansashealthwave.org)

Kansas' Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Kansas Department of Social and Rehabilitation Services**

[www.srskansas.org/services.htm](http://www.srskansas.org/services.htm)

Complete index of services offered by the agency including disability determination, community-based services, mental health services, Medicaid, etc.

#### **Make a Difference Information Network**

[www.makeadifferenceks.org](http://www.makeadifferenceks.org)

The Make a Difference Information Network (MADIN) is a collaborative effort among the Kansas Department of Health and Environment, the Kansas State Board of Education, the Kansas Department of Social and Rehabilitation Services, and Oral Health Kansas to connect Kansans with resources and services for individuals with disabilities.

### *Community Resources*

#### **Assistive Technology for Kansans Project (ATK)**

<http://atk.ku.edu>

ATK helps persons with disabilities find ways to live and work independently through the use of assistive devices and services. Guidance on supported/sheltered work and for obtaining assistive technology through five regional Assistive Technology Access Sites.

#### **Disability Rights Center of Kansas (DRC)**

[www.drckansas.org](http://www.drckansas.org)

Provides disability rights advocacy for consumers to general medical services including Medicaid, Medicare, long-term care, mental health services, and home and community-based services.

#### **Families Together, Inc.**

[www.familiestogetherinc.org](http://www.familiestogetherinc.org)

Serves families of children and youth with exceptional needs through four regional centers. Programs include the Parent Training and Information Center, Family to Family Health Information Center and the Parent to Parent support program.

## KENTUCKY

### *State Agencies*

**Cabinet for Health and Family Services – Department for Medicaid Services**  
[www.chfs.ky.gov/dms/default.htm](http://www.chfs.ky.gov/dms/default.htm)

Entry point for Kentucky's Medicaid program including links to covered services and enrollment procedures.

**State Department of Education: Special Education**

<http://www.education.ky.gov/KDE/Instructional+Resources/Exceptional+Children/default.htm>

Information hub for Kentucky's Special Education programs with links to Parent Involvement, Dispute Resolution and Forms and Documents.

**Kentucky Children's Health Insurance Program**

[kidshealth.ky.gov/en/kchip](http://kidshealth.ky.gov/en/kchip)

Kentucky's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**Kentucky Cabinet for Health and Family Services – Department for Behavioral Health, Developmental and Intellectual Disabilities**

[www.mhmr.ky.gov/mhsas/ofl.asp](http://www.mhmr.ky.gov/mhsas/ofl.asp)

Family Leadership (OFL) webpage offers links to children's service coordinators by county. Focus is primarily on mental health services.

**Kentucky Cabinet for Health and Family Services – Commission for Children with Special Healthcare Needs**

[www.chfs.ky.gov/ccshcn/About.htm](http://www.chfs.ky.gov/ccshcn/About.htm)

Information on clinical programs available to children needing special medical care who meet financial guidelines.

### *Community Resources*

**Kentucky Special Parent Involvement Network KY-SPIN**

<http://www.kyspin.com>

Parent Training and Information project that promotes self advocacy through a Family to Family training model. Resource guide, workshops and advocates available. Offers a transition program for young people, ages 14-21, who are non-diploma bound.

**The Family Information Network on Disabilities – FIND of Louisville**

<http://www.findoflouisville.org>

Provides information, training, referral, and advocacy to parents of children with disabilities and special needs, birth to age 26, and all disabilities (i.e. physical, cognitive, behavioral, and emotional).

## **LOUISIANA**

### ***State Agencies***

**Louisiana Health Services Financing – General Medicaid**  
[www.dhh.louisiana.gov/offices/page.asp?id=92&detail=4125](http://www.dhh.louisiana.gov/offices/page.asp?id=92&detail=4125)

Louisiana's Medicaid program for persons under age 19 with disabilities. Includes links to application and printable flyer on services and eligibility.

**Louisiana Department of Education – Special Populations**  
<http://www.doe.state.la.us/lde/eia/2826.html>

Information hub for Louisiana's Special Education programs and a link to an Access Guide.

**LaCHIP Processing Office**  
[www.dhh.state.la.us/offices/?ID=119](http://www.dhh.state.la.us/offices/?ID=119)

Louisiana's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**The Office for Citizens with Developmental Disabilities (OCDD)**  
<http://www.dhh.louisiana.gov/offices/page.asp?ID=77&Detail=3255>

Overview of Louisiana's support and services for persons with disabilities. Office that conducts disability determinations for purposes of SSI and Medicaid Home and Community-based Waiver programs. Services provided through 9 regional offices that can be found on the Waiver Supports and Services webpage.

**Louisiana Department of Health and Hospitals – Office of Mental Health**  
<http://www.dhh.louisiana.gov/offices/locations.asp?ID=62>

Services locator by parish including 24-hour emergency mental health services.

### ***Community Resources***

**The Advocacy Center**  
[www.advocacyla.org](http://www.advocacyla.org)

The Advocacy Center has a staff of lawyers, paralegals, client advocates and support staff who assist persons with disabilities to obtain appropriate education and to access public benefits through resources and referrals.

**Louisiana Parent Training and Information Center (LaPTIC)**  
<http://www.laptic.org/index.php>

Louisiana Parent Training and Information Center provides information, referrals, and assistance to parents of children with disabilities through individual consultations by phone, email, and in person. Also provides in person support at meetings such as IFSPs, IEPs, and ITPs and parent trainings.

**Pyramid Community Parent Resource Center**  
[www.pyramidparentcenter.org](http://www.pyramidparentcenter.org)

Assistance for New Orleans parents of children with disabilities in the areas of special education and positive behavior support at school through workshops and trainings.

## **MAINE**

### ***State Agencies***

#### **Maine Department of Health and Human Services – Office of Maine Care Services**

[www.maine.gov/dhhs/oms/member\\_index.html](http://www.maine.gov/dhhs/oms/member_index.html)

Information hub for Maine's health insurance program (formerly Medicaid) with links to care options, applications, member handbook, covered services and special eligibility options (waiver programs). Site includes Maine's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Maine Department of Education: Special Education**

<http://www.maine.gov/education/speced/index.htm>

Overview of Maine's Special Education programs, rules and due process regulations.

#### **Maine Office of the Department of Health and Human Services Child and Family Services – Children's Behavioral Health Services**

[www.maine.gov/dhhs/ocfs/cbhs](http://www.maine.gov/dhhs/ocfs/cbhs)

Provides information and referrals for children to their 21st birthday. Includes crisis hotlines, links to county offices and evaluation sites, and eligibility information.

### ***Community Resources***

#### **ALL-TECH**

[www.alltech-tsi.org](http://www.alltech-tsi.org)

A nationally recognized center that provides training, consultation, resources, and technical assistance in the areas of assistive technology, specialized software, Web accessibility, etc. Assists in identifying and funding technological solutions to many of the educational, daily living, communication, and workplace issues presented by disabilities.

#### **C.A.R.E.S., Inc**

[www.caresinc.org](http://www.caresinc.org)

Client Assistance Program that provides information, assistance and advocacy to people with disabilities who are applying for or receiving services, including Vocational Rehabilitation, Independent Living Services and Projects with Industry.

#### **Maine CITE**

[www.mainecite.org](http://www.mainecite.org)

Coordinating center that helps Maine residents get, keep and use the assistive and universally designed technology they need.

#### **Maine Disability Rights Center**

[www.maine.gov/dhhs/oes/resource/disab\\_rights.htm](http://www.maine.gov/dhhs/oes/resource/disab_rights.htm)

Direct advocacy assistance, information and referrals, and training for persons with disabilities and their families.

#### **Maine Parent Federation, Inc.**

<http://www.mpf.org>

Statewide private non-profit organization that provides information, advocacy, education, and training. Links to Fact Sheets on special education topics including state resources, testing preparation, IEPs, supported employment, and others.

#### **Pine Tree Society**

<http://www.pinetreesociety.org>

Pine Tree Society helps young people in Maine with disabilities through case management, audiology, communication services, and community services.

## MARYLAND

### *State Agencies*

#### **Maryland Medical Programs**

[www.dhmf.state.md.us/mma](http://www.dhmf.state.md.us/mma)

Entry point for Maryland's Medical Assistance Programs, including Medicaid, Home and Community-based Long Term Care, and the Children's Health Insurance Program (CHIP) which offers affordable health insurance to youth and teens not eligible for Medicaid.

#### **Maryland State Department of Education: Special Education and Early Intervention Services**

[www.marylandpublicschools.org/MSDE/divisions/earlyinterv](http://www.marylandpublicschools.org/MSDE/divisions/earlyinterv)

Coordinates support and information activities for families of children with disabilities from birth through age 21 through local Family Support Networks, Preschool Partners, and Partners for Success Resource Centers. Includes due process branch for special education mediation support.

#### **Maryland Children's Health Insurance Program (MCHIP)**

[www.dhmf.state.md.us/mma/mchp](http://www.dhmf.state.md.us/mma/mchp)

Maryland's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Maryland State Department of Health and Mental Hygiene: Developmental Disabilities Administration**

[www.ddamaryland.org](http://www.ddamaryland.org)

Information hub for Maryland's Developmental Disabilities services, including disability determination services, waiver services and respite care, which are obtained through regional offices listed on the website under Services.

#### **Maryland Department of Disabilities**

[www.mdtdap.org](http://www.mdtdap.org)

MDOD is the department that oversees Maryland's disability benefits such as SSI and daily support services such as Healthcare, Mental Health Services, Personal Assistance Services, Pharmacy Assistance and Family Support.

#### **Maryland State Department of Health and Mental Hygiene: Children's Medical Services Program (CMS)**

[www.fha.maryland.gov/genetics/specialcare.cfm](http://www.fha.maryland.gov/genetics/specialcare.cfm)

Specialty care for low-income, uninsured or underinsured Marylanders, ages 0-21 years, with a chronic illness or disability. Family-centered, community-based systems of care, coordinated through county offices, listed under Specialty Care and Regional Resources Development.

#### **Maryland State Department of Education – Division of Rehabilitation Services – Client Assistance Program**

[www.dors.state.md.us/DORS/ProgramServices/cap](http://www.dors.state.md.us/DORS/ProgramServices/cap)

Program that helps individuals who have concerns or difficulties when applying for or receiving rehabilitation services, including vocational rehabilitation, supported employment, and independent living.

### *Community Resources*

#### **The Coordinating Center (for individuals with complex medical needs and disabilities)**

[www.coordinatingcenter.org](http://www.coordinatingcenter.org)

Coordinates all services for individuals with complex medical needs through a Medicaid waiver program.

#### **Family NET Works**

<http://www.family-networks.org/index.cfm>

Online resource for disability-related information and support specific to the needs of Maryland families. Includes information on applying for services, parent mentors and training events.

#### **Kennedy Krieger Institute**

[www.kennedykrieger.org](http://www.kennedykrieger.org)

Organization with 35 outpatient clinics serving children and adolescents with disorders of the brain, spinal cord and musculoskeletal system and the Kennedy Krieger School which addresses the special education and related service needs of students, ages 6-21 years, who exhibit a wide range of learning, developmental and neurological disorders.

**Maryland Disability Law Center**

[www.mdlcbalto.org](http://www.mdlcbalto.org)

Advocates who assist in getting Disability, Medicaid and Special Education benefits.

**The Parents' Place of Maryland**

[www.ppm.org/index.asp](http://www.ppm.org/index.asp)

A Parent Training and Information Center helping families of children with disabilities across the state of Maryland.

**Transition to Adult Healthcare Self Advocacy Project**

[www.resourcefinder.kennedykrieger.org/pdfs/mentor.pdf](http://www.resourcefinder.kennedykrieger.org/pdfs/mentor.pdf)

A mentor/mentee program designed for youth, ages 14 years through 25 years with developmental disabilities and other special healthcare needs, who are interested in understanding their diagnosis and controlling their healthcare.



## **MASSACHUSETTS**

### ***State Agencies***

#### **Massachusetts Office of Health and Human Services**

[www.mass.gov](http://www.mass.gov)

Information hub for Massachusetts' government services, including Medicaid, special education, healthcare, disabilities and more, found under "Residents" tab.

#### **Massachusetts Office of Health and Human Services – Medicaid and MassHealth**

[www.mass.gov/?pageID=eohhs2constituent&L=2&L0=Home&L1=Consumer&sid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2constituent&L=2&L0=Home&L1=Consumer&sid=Eeohhs2)

Entry point for Massachusetts's combined Medicaid and Children's Health Insurance Program (CHIP) – MassHealth.

#### **Massachusetts Department of Elementary and Secondary Education: Special Education**

[www.doe.mass.edu/sped](http://www.doe.mass.edu/sped)

Information on Massachusetts's Special Education programs with links to IEP forms and notices, mediation and appeals, and other resources.

#### **Department of Developmental Services – Children**

[www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2)

Services and support for children with developmental disabilities. Information found in menu under Consumers, then Disability Services.

#### **State Mental Health Representative for Children and Youth**

[www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2)

Services and support for children with behavioral health issues. Information found in menu under Consumers, then Behavioral Health.

#### **Home Modifications Loan Program (HMLP)**

[www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2)

No – and low-interest loans to modify the homes of adults and children with disabilities. Includes program description, provider agencies and eligibility requirements. Information found in menu under Consumer, then Disability Services, then Housing.

### ***Community Resources***

#### **The Federation for Children with Special Needs**

[www.fcsn.org/index.php](http://www.fcsn.org/index.php)

The Federation is a center for parents and parent organizations to work together on behalf of children with special needs and their families. Incorporates a Parent Training and Information Center for Massachusetts' parents of disabled children, provides free, personalized advocacy, information and technical assistance related to special education law, community resources and more.

#### **Family TIES of Massachusetts**

[www.massfamilyties.org/index.php](http://www.massfamilyties.org/index.php)

Parent-to-parent support, information and referral services, and workshops on topics from Early Intervention through transition to adulthood. Sections on transition services and a mental health how-to guide. Found in Regional Offices of the Massachusetts Department of Public Health.

#### **Massachusetts Families Organizing for Change**

[www.mfofc.org/index.html](http://www.mfofc.org/index.html)

The mission of MFOFC is to provide sustained advocacy and leadership training in pursuit of high quality, individualized community support and service options, including family support for people with disabilities and their families.

#### **MassMatch**

[www.massmatch.org](http://www.massmatch.org)

State assistive technology program with links to ads for used equipment, regional training centers and alternative financing programs.

New England INDEX  
[www.disabilityinfo.org](http://www.disabilityinfo.org)

Extensive index of resources for people with disabilities maintained by the Shriver Center of UMASS Medical School. Includes an "Ask Index" feature for information requests.

## MICHIGAN

### *State Agencies*

#### Michigan Office of Community Health – Medicaid

[www.michigan.gov/mdch/0,1607,7-132-2943\\_4860---,00.html](http://www.michigan.gov/mdch/0,1607,7-132-2943_4860---,00.html)

Entry point for Michigan's Medicaid program, including links to covered services and enrollment procedures.

#### Michigan Department of Education – Special Education and Early Intervention Services

[http://www.michigan.gov/mde/0,1607,7-140-6530\\_6598---,00.html](http://www.michigan.gov/mde/0,1607,7-140-6530_6598---,00.html)

Links to administrative forms and procedures, assessment, due process, etc. are found in the left column under Offices/ Special Education and Early Intervention Services.

#### Michigan Department of Community Health – MICHild

[www.michigan.gov/mdch/0,1607,7-132-2943\\_4845\\_4931---,00.html](http://www.michigan.gov/mdch/0,1607,7-132-2943_4845_4931---,00.html)

Michigan's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### Michigan Department of Community Health – Mental Health and Developmental Disability

[www.michigan.gov/mdch/0,1607,7-132-2941\\_4868\\_4897---,00.html](http://www.michigan.gov/mdch/0,1607,7-132-2941_4868_4897---,00.html)

Michigan's services to persons with developmental disabilities are provided through local Community Mental Health Service Programs (CMHSPs). Link to local resource locator.

#### Michigan Department of Community Health – Children's Special Health Care Services (CSHCS)

[www.michigan.gov/mdch/0,1607,7-132-2942\\_4911\\_35698-15087--,00.html](http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_35698-15087--,00.html)

Provides specialty medical services, family center services and community-based services to help disabled children and adults remain in their homes. Link to local offices which establish the qualifying medical condition and administer the services.

#### Michigan Department of Community Health – Children with Special Needs Fund

[http://www.michigan.gov/mdch/0,1607,7-132-2942\\_4911\\_35698-56806--,00.html](http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_35698-56806--,00.html)

Provides partial or full funding for wheelchair ramps into homes, van lifts and tie downs, air conditioners, and therapeutic tricycles. Link to application.

### *Community Resources*

#### Association for Children's Mental Health

[www.acmh-mi.org](http://www.acmh-mi.org)

Association that advocates for appropriate services for children and youth with emotional and behavioral disorders. Works in partnership with the Department of Community Health, Family Independence Agency, Community Mental Health Authorities, Family Court, the Department of Education and local school districts.

#### Center for Educational Networking

[www.cenmi.org/matr](http://www.cenmi.org/matr)

Special Education rules and facts, Directory of Service Providers for Infants, Toddlers, and Students With Disabilities, links to Michigan organizations serving students with disabilities including organizations that provide assistive technology.

#### Citizens Alliance to Uphold Special Education (CAUSE)

[www.causeonline.org](http://www.causeonline.org)

Parent Training and Information Center (PTI) on special education issues.

#### Michigan Alliance for Families

[www.michiganallianceforfamilies.org](http://www.michiganallianceforfamilies.org)

Information, support and education for families of children and adults with disabilities from birth to age 26. Provides information, support and resources at regional sites to increase the involvement of parents in decisions about their children's education.

#### Michigan's Assistive Technology Program

[www.copower.org/AT/index.htm](http://www.copower.org/AT/index.htm)

Device demonstrations, training and low or no interest loan programs.

**Michigan Association for Children with Emotional Disorders**

[www.michkids.org](http://www.michkids.org)

Helps families find educational, mental health, and other services for teens with emotional and behavioral disorders.

**Michigan Protection and Advocacy Service, Inc.**

[www.mpas.org](http://www.mpas.org)

Assistance with obtaining Social Security benefits, Medicaid, Medicare and other insurance, Vocational Rehabilitation and other issues for persons with disabilities.

**Michigan Special Education Mediation Program**

[www.cenmi.org/msemp](http://www.cenmi.org/msemp)

Facilitation and mediation services for the special education process including eligibility for services, evaluation results and IEP team meetings.

## MINNESOTA

### *State Agencies*

Minnesota Department of Human Services – Medical Assistance (Medicaid)  
[www.dhs.state.mn.us/main/idcplg?IdcService=GET\\_DYNAMIC\\_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id\\_006254#](http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_006254#)

Entry point for Minnesota's Medicaid program including links to covered services and enrollment procedures.

#### Minnesota Care

[www.dhs.state.mn.us/main/idcplg?IdcService=GET\\_DYNAMIC\\_CONVERSION&dDocName=id\\_006255&RevisionSelectionMethod=LatestReleased](http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&dDocName=id_006255&RevisionSelectionMethod=LatestReleased)

Minnesota's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### Minnesota Department of Human Services – Minnesota Healthcare Programs Children with Disabilities

[www.dhs.state.mn.us/main/idcplg?IdcService=GET\\_DYNAMIC\\_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id\\_006251](http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_006251)

Information about Minnesota's healthcare programs for children with disabilities including TEFRA and waiver programs.

#### Minnesota Department of Health – Children with Special Health Needs (MCSHN)

[www.health.state.mn.us/mcshn](http://www.health.state.mn.us/mcshn)

Links to medical and rehabilitative assessments and services available in local communities.

### *Community Resources*

#### Courage Center

[www.couragecenter.org](http://www.couragecenter.org)

Organization which offers occupational and physical therapy, vocational rehabilitation and more to children and youth with disabilities. Also offers accessible sports and recreation programs.

#### PACER Center, Inc.

[www.pacer.org](http://www.pacer.org)

Parent Training and Information Center offering parent to parent mentoring, resources and online training programs. Part of the national Pacer Center organization.

## MISSISSIPPI

### *State Agencies*

#### Mississippi Division of Medicaid

[www.medicaid.ms.gov](http://www.medicaid.ms.gov)

Information hub for Mississippi's Medicaid programs, including the Children's Health Insurance Program (CHIP), Disabled Child Living at Home Program, and Home and Community-based Waiver Programs.

#### Mississippi Department of Education – Office of Special Education – Just for Parents

[www.mde.k12.ms.us/special\\_education/just\\_for\\_parents.html](http://www.mde.k12.ms.us/special_education/just_for_parents.html)

Articles and publications explaining Mississippi's special education programs and procedures.

#### Mississippi's Children's Health Insurance Plan (CHIP)

[www.msdh.state.ms.us/msdhsite/\\_static/41,0,96.html](http://www.msdh.state.ms.us/msdhsite/_static/41,0,96.html)

Mississippi's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### Mississippi Department of Mental Health – Developmental Disabilities

[http://www.dmh.state.ms.us/mental\\_retardation.htm](http://www.dmh.state.ms.us/mental_retardation.htm)

Links to programs for children with developmental disabilities. Services and program locations outlined in the Intellectual and Developmental Disabilities State Plan which can be accessed from that website.

#### Mississippi State Department of Health: Children's Medical Program

[www.msdh.state.ms.us/msdhsite/\\_static/41,0,163.html](http://www.msdh.state.ms.us/msdhsite/_static/41,0,163.html)

Organizes pediatric specialty care, physical/occupational therapy, durable medical equipment, etc. for disabled children to age 20, through pediatric social workers at local health departments. Eligibility requirements listed.

### *Community Resources*

#### EMPOWER Community Resource Center

[www.msempower.org](http://www.msempower.org)

Parent Training Center on special education issues. Information and workshops about the range of options, programs, services, and resources available at the national, state, and local levels for children with disabilities and their families.

#### Mississippi Family as Allies for Children Mental Health, Inc.

<http://www.msfaacmh.org>

Information, services and emotional support to families and youth with mental health issues. Toll free crisis line, family respite services and more listed under Programs & Services.

#### Mississippi Protection and Advocacy System

[www.mspas.com](http://www.mspas.com)

Protection and advocacy for individuals with developmental disabilities in the areas of education, employment, housing, denial of services or denial of access.

#### Mississippi Society for Disabilities

[www.msdisabilities.com](http://www.msdisabilities.com)

Client assistance in the area of vocational rehabilitation. Program provides physical, occupational and speech-language therapies. Offers a Specific Assistance Program to help pay for assistive aids, travel to out of town specialists, and assisted recreation.

#### Parents United Together

<http://www.parentsunitedtogether.com>

Parent Training and Information Center offering information and support groups for disability issues.

## MISSOURI

### *State Agencies*

**Missouri Department of Social Services – MO HealthNet for Kids**  
[www.dss.mo.gov/mhk/index.htm](http://www.dss.mo.gov/mhk/index.htm)

Portal to Missouri's medical services programs, including MO HealthNet (Medicaid), and the State Children's Health Insurance Program (SCHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**Department of Elementary and Secondary Education – Special Education**  
[www.dese.mo.gov/divspeced/parentresources.html](http://www.dese.mo.gov/divspeced/parentresources.html)

Information about Missouri's Special Education program and resources for parents.

**Missouri Department of Mental Health – Division of Developmental Disabilities FAQs**  
[www.dmh.mo.gov/mrdd/new/consumer1.htm](http://www.dmh.mo.gov/mrdd/new/consumer1.htm)

Information about services provided to persons with developmental disabilities. Links to regional office locations where applications are accepted and processed.

**Department of Health and Senior Services: Children with Special Healthcare Needs**  
[www.dhss.mo.gov/SHCN/CSHCN.html](http://www.dhss.mo.gov/SHCN/CSHCN.html)

Preventive, diagnostic and treatment services for children and youth with disabilities, coordinated through 13 regional offices. Services include physical, occupational and speech therapies.

### *Community Resources*

**Missouri Parents Act: MPACT**  
<http://ptimpact.org/About/About.aspx>

Parent Training and Information Center on special education Issues. Offers online resources and training events at regional locations.

**Missouri Protection and Advocacy Services**  
[www.moadvocacy.org](http://www.moadvocacy.org)

Assistance in obtaining services for persons with disabilities in the areas of Special Education and SSI, among others.

**Sharing Our Strength: SOS**  
[www.sharingourstrengths.com](http://www.sharingourstrengths.com)

Parent to parent mentoring and support network for parents of children with developmental disabilities or special healthcare needs.

## MONTANA

### *State Agencies*

Montana Department of Public Health & Human Services – Medicaid

[www.dphhs.mt.gov/programsservices/medicaid.shtml](http://www.dphhs.mt.gov/programsservices/medicaid.shtml)

FAQs, eligibility and qualifying information, applications and forms.

Montana Office of Public Instruction – Children with Special Needs

[www.opi.state.mt.us](http://www.opi.state.mt.us)

Portal to Montana's Special Education programs, in the top menu under Parents, then Special Needs.

Montana Children's Health Insurance Program (MCHIP)

[www.chip.mt.gov](http://www.chip.mt.gov)

Montana's Children's Health Insurance Program (CHIP) which offers affordable health and dental insurance for children and teens not eligible for Medicaid.

Montana Department of Public Health & Human Services – Developmental Disabilities

[www.dphhs.mt.gov/dsd](http://www.dphhs.mt.gov/dsd)

Links to information on Programs, Services, and Disability Determination Services. Regional/County office locator is found under Contact Us in the top menu bar.

Montana Department of Public Health & Human Services – Children's Mental Health

[www.dphhs.mt.gov/mentalhealth/children/index.shtml](http://www.dphhs.mt.gov/mentalhealth/children/index.shtml)

Mental health services for children under age 18 provided through Medicaid, MCHIP, or the Supplemental Services Plan.

Montana Department of Public Health & Human Services – Children's Special Health Services

<http://www.dphhs.mt.gov/PHSD/family-health/cshs/cshs-index.shtml>

Access to pediatric specialty clinics and other services for children with disabilities. Eligibility and application information found under Financial Assistance in the left column menu.

### *Community Services*

Disability Rights Montana

[www.disabilityrightsmt.org](http://www.disabilityrightsmt.org)

Assistance for persons with disabilities to obtain services in the areas of special education, care and treatment, assistive technology and government benefits such as Medicaid and SSI.

Parents, Let's Unite For Kids (PLUK)

[www.pluk.org](http://www.pluk.org)

Parent Training and Information Center offering information, resources and training to parents of children with disabilities.

The University of Montana Rural Institute: Transition Project

<http://ruralinstitute.umt.edu/transition/default.asp>

Transition services for youth with disabilities in rural areas of Montana. Includes supported and customized employment services.



## NEBRASKA

### *State Agencies*

#### Nebraska Department of Public Health & Human Services – Medicaid

[www.hhs.state.ne.us/med/medindex.htm](http://www.hhs.state.ne.us/med/medindex.htm)

FAQs, eligibility and qualifying information, applications and forms.

#### Nebraska Department of Education – Special Populations

[www.nde.state.ne.us/SPED/sped.html](http://www.nde.state.ne.us/SPED/sped.html)

Information about Nebraska's Special Education programs. Links to forms, mediation procedures and a Parent's Rights Guide.

#### Kids Connection

[www.hhs.state.ne.us/med/kidsconx.htm](http://www.hhs.state.ne.us/med/kidsconx.htm)

Nebraska's Children's Health Insurance Program (CHIP) offers affordable health and dental insurance for children and teens not eligible for Medicaid.

#### Nebraska Department of Health and Human Services: Home and Community Services

[www.hhss.ne.gov/hcs](http://www.hhss.ne.gov/hcs)

Links to Nebraska's programs and services for persons with disabilities including Disabled Medicaid Waiver, Disabled Children's Program (DCP), Disabled Persons and Family Support Program, and the Medically Handicapped Children's Program.

#### The Assistive Technology Partnership (ATP)

[www.atp.ne.gov](http://www.atp.ne.gov)

Identification of assistive technology solutions and help in locating funding.

#### Nebraska Client Assistance Program

[www.cap.ne.gov:3000/hotline\\_services](http://www.cap.ne.gov:3000/hotline_services)

Information and referral for Nebraskans who have questions or concerns related to a disability.

### *Community Resources*

#### Answers 4 Families

[www.answers4families.org](http://www.answers4families.org)

A partnership of the Nebraska Department of Health & Human Services and the University of Nebraska, Lincoln's Center on Children, Families, and the Law that offers expert information on Nebraska's programs for children with special needs.

#### AT4ALL.COM

[www.at4all.com](http://www.at4all.com)

Quality used assistive technology – computers, wheelchairs & scooters, walkers, personal care items, etc.

#### Parent Training and Information Nebraska

[www.pti-nebraska.org](http://www.pti-nebraska.org)

Parent to parent mentoring, information and training for parents of children with disabilities in the area of special education.

#### Parent to Parent Network

[www.parent-parent.org](http://www.parent-parent.org)

Volunteer support groups for parents of children with disabilities throughout Nebraska.

## NEVADA

### ***State Agencies***

Nevada Department of Public Health & Human Services – Division of Healthcare Financing and Policy – Medicaid

<http://dhcfp.state.nv.us>

FAQs, eligibility and qualifying information, applications and forms are found in the left column menu.

Nevada Department of Education: Special Education

<http://nde.doe.nv.gov/SpecialEducation.htm>

Information about Nevada's Special Education programs. Parent's Rights Guide is found in Special Education, then Resources, in the left column menu.

Division of Healthcare Financing and Policy – Nevada Check Up

[www.nevadacheckup.state.nv.us](http://www.nevadacheckup.state.nv.us)

Nevada's Children's Health Insurance Program (CHIP) which offers affordable health and dental insurance for children and teens not eligible for Medicaid.

Nevada Department of Health and Human Services – Disability Services

[http://dhhs.nv.gov/ODS\\_DisabilityServices.htm](http://dhhs.nv.gov/ODS_DisabilityServices.htm)

Services for persons with physical disabilities including assistive technology, personal assistants, etc.

Children with Special Healthcare Needs (CSHCN)

[www.health.nv.gov/CSHCN.htm](http://www.health.nv.gov/CSHCN.htm)

Portal to Nevada's programs for children with disabilities with links to medical programs, Medicaid Waiver programs, school-based programs, parent support programs, etc.

Nevada Department of Health and Human Services – Division of Mental Health and Developmental Services

<http://mhds.state.nv.us>

Links to Nevada's programs for persons with developmental disabilities found at the bottom of the page. Services delivered through three regional centers.

Project Assist

[www.health.nv.gov/CSHCN\\_FindingResources\\_ProjectAssist.htm](http://www.health.nv.gov/CSHCN_FindingResources_ProjectAssist.htm)

Information source and database of resources for children and young adults with disabilities and their families. Call for a phone interview and a Project ASSIST staff person will send you a list of state and national programs and resources available for your family.

### ***Community Resources***

Disability Resources, Inc.

<http://disabilityresourcesonline.org>

Washoe County based non-profit organization that assists with supported employment and provides respite services.

Family TIES of Nevada

[www.familytiesnv.org](http://www.familytiesnv.org)

Healthcare Information and Education Center that assists families of children with disabilities to understand and navigate health systems and insurance plans.

Nevada Disability Advocacy and Law Center

<http://www.ndalc.org>

Assistance for children and youth with disabilities to obtain special education and transition services.

Nevada PEP

[www.nvpep.org/template.php?page=front](http://www.nvpep.org/template.php?page=front)

Nevada's statewide Parent Training & Information Center for families of children with disabilities. Parent mentors and advocates are available to assist with special education issues.

## NEW HAMPSHIRE

### *State Agencies*

New Hampshire Department of Public Health & Human Services – Medicaid  
[www.dhhs.state.nh.us/DHHS/MEDICAIDPROGRAM/default.htm](http://www.dhhs.state.nh.us/DHHS/MEDICAIDPROGRAM/default.htm)

FAQs, eligibility and qualifying information, applications and forms are found in the top menu bar.

New Hampshire Department of Education – Bureau of Special Education  
<http://www.ed.state.nh.us/education/doe/organization/instruction/bose.htm>

Information and links to documents on New Hampshire's Special Education programs.

Bureau of Developmental Services – Area Agencies  
<http://www.dhhs.state.nh.us/DHHS/BDS/support-agencies.htm>

List of offices that coordinate services for children with developmental disabilities.

New Hampshire Healthy Kids  
[www.nhhealthykids.com](http://www.nhhealthykids.com)

New Hampshire's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

New Hampshire Department of Education – Laws and Hearings/Mediation  
[www.ed.state.nh.us/education/laws/hearinginfo.htm](http://www.ed.state.nh.us/education/laws/hearinginfo.htm)

Link to Users Guide to Administrative Process and other information.

New Hampshire Department of Health and Human Services: Special Medical Services (SMS)  
[www.dhhs.state.nh.us/DHHS/SPECIALMEDSRVCS/sms-shc-children.htm](http://www.dhhs.state.nh.us/DHHS/SPECIALMEDSRVCS/sms-shc-children.htm)

Specialty healthcare services for children with disabilities. Specialty clinics include therapy for neuro-motor disorders and speech and swallowing disorders.

### *Community Resources*

Disabilities Rights Center, Inc.  
[www.drcnh.org](http://www.drcnh.org)

Information, referral, advice, and legal representation and advocacy for individuals with disabilities in the areas of special education, medical and financial assistance, etc.

Education-A-Must  
[www.education-a-must.com](http://www.education-a-must.com)

Advocacy service that works with school districts and local, state & federal agencies to secure the necessary services and education for all who qualify.

Institute on Disability/UCED – Assistive Technology in New Hampshire – ATinNH  
[www.iod.unh.edu/technology.html](http://www.iod.unh.edu/technology.html)

Help in obtaining assistive technology through equipment re-use, loans, and low cost funding alternatives.

The New Hampshire Challenge, Inc.  
[www.nhchallenge.org/about.asp](http://www.nhchallenge.org/about.asp)

Offers news and information about disability issues and links to state agencies and local resources under the Find Help menu listing.

New Hampshire Family Voices  
[www.nhfv.org](http://www.nhfv.org)

Parent-run center that provides free technical assistance in navigating the maze of public and private services for children and youth with special healthcare needs.

Parent Information Center (PIC)  
[www.picnh.org](http://www.picnh.org)

Parent Training and Information Center that offers parent to parent mentoring, training and information on special education issues.

**The Parent Information Center on Special Education**

<http://www.nhspecialed.org>

Information on New Hampshire's special education laws, regulations and best practices.

**Parent to Parent**

[www.p2pnh.org](http://www.p2pnh.org)

Parent mentoring and support program.

## NEW JERSEY

### *State Agencies*

**New Jersey Department of Human Services – Division of Medical Assistance & Health Services – Medicaid**

[www.state.nj.us/humanservices/dmahs/clients/medicaid](http://www.state.nj.us/humanservices/dmahs/clients/medicaid)

Eligibility and qualifying information. Links to county welfare offices where applications are processed.

**Office of Special Education Programs**

[www.state.nj.us/education/specialed](http://www.state.nj.us/education/specialed)

Information and links to New Jersey's Special Education programs.

**New Jersey Family Care**

[www.njfamilycare.org](http://www.njfamilycare.org)

New Jersey's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**NJHelps**

[www.njhelps.org](http://www.njhelps.org)

Information about qualifying for 28 state and federal programs administered through the Department of Human Services and its partners in the areas of housing, employment, child care, health insurance, prescriptions, etc.

**New Jersey Department of Human Services – Division of Developmental Disabilities**

[www.state.nj.us/humanservices/ddd/home](http://www.state.nj.us/humanservices/ddd/home)

Information about New Jersey's major programs and initiatives for persons with disabilities, including the Medicaid Community Care Waiver and Family Support Services for families caring for a disabled child.

**New Jersey Department of Children and Families – Division of Child Behavioral Health Services**

[www.state.nj.us/dcf/behavioral](http://www.state.nj.us/dcf/behavioral)

Access point for child and youth mental health services.

**New Jersey Department of Health and Senior Services – Special Child Health Services**

[www.state.nj.us/health/fhs/sch/index.shtml](http://www.state.nj.us/health/fhs/sch/index.shtml)

Assistance for families caring for children with complex, long-term medical and developmental disabilities. Link to Child Evaluation Centers where services are coordinated.

### *Community Resources*

**Association for Special Children and Families**

[www.ascfamily.org](http://www.ascfamily.org)

Community organization offering training, resources and links for parents of children with disabilities.

**Disability Rights New Jersey**

[www.drnj.org](http://www.drnj.org)

Client Assistance Program offering information and referrals on a broad range of advocacy services including legal representation in the area of special education law. Includes the Assistive Technology Advocacy Center which assists people with disabilities to obtain assistive technology devices and/or services.

**Family Support Center of New Jersey**

[www.fscnj.org](http://www.fscnj.org)

Clearinghouse for up-to-date information on national, state and local family support programs and services for disabilities.

**New Jersey Statewide Parent-to-Parent**

[www.spannj.org/familywrap/parent2parent.htm](http://www.spannj.org/familywrap/parent2parent.htm)

Statewide network of parents offering training, emotional support and information to families of children with developmental delays, disabilities, and special health needs.

### Sparkle of UCP

[www.geocities.com/sparkleofucp](http://www.geocities.com/sparkleofucp)

Supportive resources for parents of children with disabilities including advocacy, information and referrals, and disability awareness presentations.

### Statewide Parent Advocacy Network (SPAN)

[www.spannj.org](http://www.spannj.org)

Parent Training and Information Center (PTI) offering information specialists who assist parents in obtaining special education services and disability benefits, parent to parent support, and youth transition services.

## NEW MEXICO

### *State Agencies*

#### **New Mexico Human Services Department – Medicaid**

[www.hsd.state.nm.us/mad/HMedicaid.html](http://www.hsd.state.nm.us/mad/HMedicaid.html)

Eligibility and qualifying information for New Mexico's Medicaid program. Online application and link to local Income Support Division (ISD) offices that determine eligibility.

#### **New Mexico Department of Education: Special Education**

[www.ped.state.nm.us/seo/index.htm](http://www.ped.state.nm.us/seo/index.htm)

Information and links to New Mexico's Special Education programs. Includes an "Especially for Parents" section with documents on special education topics.

#### **Insure New Mexico Solutions – New MexiKids**

[www.insurenewmexico.state.nm.us/NewMexiKidsandTeens.htm](http://www.insurenewmexico.state.nm.us/NewMexiKidsandTeens.htm)

New Mexico's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

### *Community Resources*

#### **New Mexico Technology Assistance Program**

[www.nmtap.com](http://www.nmtap.com)

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

#### **Parents Reaching Out**

<http://www.parentsreachingout.org>

Parent Training and Information Center that offers workshops, trainings and parent mentors to help with issues related to special education and disability benefits. Includes extensive links to resources.

#### **UNM Center for Development and Disability – Disability Resource Directory**

<http://cdd.unm.edu/infocenternm>

New Mexico resources for persons with disabilities. Telephone referral specialists and online resource directory by area. Medicaid and state program tip sheets.

## NEW YORK

### *State Agencies*

New York State Department of Health – Medicaid  
[www.newyorkhealth.gov/health\\_care/medicaid/index.htm](http://www.newyorkhealth.gov/health_care/medicaid/index.htm)  
FAQs, eligibility and qualifying information, applications and forms.

Vocational and Educational Services for Individuals with Disabilities (VESID)  
<http://www.vesid.nysed.gov>

Website for all New York State special education and vocational programs. Information specifically for parents found in left column menu under Special Education, then Help for Parents.

#### Child Health Plus

New York State Health Department  
[www.health.state.ny.us/nysdoh/chplus/index.htm](http://www.health.state.ny.us/nysdoh/chplus/index.htm)

New York's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

New York State Office of Mental Retardation and Developmental Disabilities  
[www.omr.state.ny.us/ws/index.jsp](http://www.omr.state.ny.us/ws/index.jsp)

Resource directory for New York's major programs and initiatives for persons with disabilities. Statewide listing of not-for-profit voluntary agencies by region according to OMRDD's Developmental Disabilities Services Offices (DDSO).

Office of Mental Health  
[www.omh.state.ny.us](http://www.omh.state.ny.us)

Links to services for children and youth with emotional problems.

New York State Commission on Quality of Care and Advocacy for Persons with Disabilities  
[www.cqcapd.state.ny.us/aboutcqcf/faqgen.htm](http://www.cqcapd.state.ny.us/aboutcqcf/faqgen.htm)

FAQs and resources for persons with disabilities who need advocacy to obtain special education services and disability benefits.

### *Community Resources*

The Advocacy Center  
[www.advocacycenter.com/index.php](http://www.advocacycenter.com/index.php)

Links to Parent Training and Information Centers, special education advocates, service coordinators and other advocacy organizations.

Advocates for Children of New York (New York City)  
[www.advocatesforchildren.org](http://www.advocatesforchildren.org)

Citywide agency offering free individual case assistance to families and children who are experiencing problems in obtaining appropriate special educational services.

The Family Resource Network, Inc  
<http://www.familyrn.org>

Parent Training and Information Center serving Broome, Chenango, Delaware, Otsego, Tioga and Tompkins Counties.

Resources for Children with Special Needs, Inc.  
<http://www.resourcesnyc.org/rhome3.php#>

Help for families to understand and negotiate educational and human service systems in New York City.

Sinergia  
[www.sinergiany.org](http://www.sinergiany.org)

Service coordination, information and support to individuals with disabilities in underserved families including many with limited English proficiency, African Americans, the homeless and families experiencing poverty.



**United We Stand of New York**

<http://www.uwsfn.org>

Community-based parent support program that serves culturally diverse families who have children with disabilities in Brooklyn and Red Hook.

**Westchester Institute for Human Development**

[www.wihd.org](http://www.wihd.org)

Programs and services in Westchester County. Includes dental services for persons with disabilities.

## NORTH CAROLINA

### *State Agencies*

#### North Carolina Division of Medical Assistance – Medicaid

[www.ncdhhs.gov/dma/medicaid/index.htm](http://www.ncdhhs.gov/dma/medicaid/index.htm)

FAQs, eligibility and qualifying information, applications and forms.

#### Public Schools of North Carolina – Exceptional Children Division Parent Resources

[www.ncpublicschools.org/ec/policy/resources](http://www.ncpublicschools.org/ec/policy/resources)

Handbook on Parent's Rights and other information about North Carolina's Special Education programs.

#### North Carolina Health Choice

[www.dhhs.state.nc.us/dma/cpcont.htm](http://www.dhhs.state.nc.us/dma/cpcont.htm)

North Carolina's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### North Carolina Department of Health and Human Services – Services for People with Disabilities

[www.ncdhhs.gov/disabilities/services.htm](http://www.ncdhhs.gov/disabilities/services.htm)

Links to state programs for persons with disabilities including advocacy services and assistive technology programs.

#### North Carolina Client Assistance Program

<http://cap.state.nc.us>

Assistance to persons with disabilities in obtaining and maintaining employment.

#### North Carolina Department of Health and Human Services – North Carolina Assistive Technology Program

[www.ncatp.org](http://www.ncatp.org)

Demonstrations, equipment loans, and funding sources for assistive technology.

#### North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services

[www.ncdhhs.gov/mhddsas/consumers.htm](http://www.ncdhhs.gov/mhddsas/consumers.htm)

Information about North Carolina's mental health services with links to local contacts and services. Downloadable consumer handbook.

### *Community Resources*

#### Disability Rights North Carolina

[www.disabilityrightsn.org](http://www.disabilityrightsn.org)

Private organization that helps people across North Carolina to gain access to services and opportunities through advocacy and legal expertise.

#### Exceptional Children's Assistance Center (ECAC, Inc.)

[www.ECAC-parentcenter.org](http://www.ECAC-parentcenter.org)

Links to Parent Training and Information and Family Health Information Centers in North Carolina. Parent to parent mentoring, training and advocacy in the areas of special education and disability services.

#### First In Families of North Carolina

[www.fifnc.org/index.html](http://www.fifnc.org/index.html)

Information, resources and support for low-income children and youth with disabilities. Services include recreational items, home furnishings or modifications, childcare or respite, repairs to vehicles, as well as support and training through local chapters.

#### F.I.R.S.T.

[www.FIRSTwnc.org](http://www.FIRSTwnc.org)

Parent Training and Information Center serving Buncombe, Haywood, Henderson, Madison, Polk, Rutherford, Transylvania and Yancey Counties with training and advocacy in the areas of special education and disability services.

**HOPE Parent Resource Center**

[www.fsnhope.org/index.php](http://www.fsnhope.org/index.php)

Parent Training and Information Center that offers parents of children with disabilities training and advocacy in the areas of special education services. Parent to parent mentoring available.

## NORTH DAKOTA

### *State Agencies*

**North Dakota Department of Human Services – Medicaid**

[www.nd.gov/dhs/services/medicalserv/medicaid](http://www.nd.gov/dhs/services/medicalserv/medicaid)

FAQs, eligibility and qualifying information, applications and forms.

**North Dakota Department of Public Instruction: Special Education – Parent Resources**

[www.dpi.state.nd.us/speced/resource/parent/index.shtm](http://www.dpi.state.nd.us/speced/resource/parent/index.shtm)

Overview of North Dakota's Special Education programs including transition services.

**Healthy Steps**

[www.nd.gov/dhs/services/medicalserv/chip](http://www.nd.gov/dhs/services/medicalserv/chip)

North Dakota's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**North Dakota Department of Human Services – Disability Services Division**

[www.nd.gov/dhs/services/disabilities](http://www.nd.gov/dhs/services/disabilities)

Links to Developmental Disabilities Services, Disability Determination Services, and rehabilitation and employment counseling.

**North Dakota Department of Human Services – Mental Health Services**

[www.nd.gov/dhs/services/mentalhealth](http://www.nd.gov/dhs/services/mentalhealth)

Mental health and substance abuse services are delivered through eight Regional Human Service Centers and the North Dakota State Hospital in Jamestown.

**North Dakota Department of Human Services – North Dakota Protection and Advocacy Project**

<http://www.ndpanda.org>

Assistance and advocacy for persons with disabilities who are having difficulties accessing education services and disabilities benefits. Information and referrals in person and over the phone.

**North Dakota Department of Human Services – Children's Special Health Services – County Social Services**

[www.nd.gov/dhs/locations/countysocialserv](http://www.nd.gov/dhs/locations/countysocialserv)

Interactive map for locating county social services offices, where applications can be made for Medicaid, children's health services, community-based services and supports, etc.

**North Dakota Department of Human Services – North Dakota Client Assistance Program**

[www.nd.gov/cap](http://www.nd.gov/cap)

Assistance for persons with disabilities to obtain and maintain employment.

**North Dakota Interagency Program for Assistive Technology**

[www.ndipat.org](http://www.ndipat.org)

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

### *Community Resources*

**Pathfinder Family Center**

[www.pathfinder-nd.org](http://www.pathfinder-nd.org)

Parent Training and Information Center that offers parents of children with disabilities training and advocacy in the areas of special education services. Parent to parent mentoring available.

## OHIO

### ***State Agencies***

Ohio Department of Job and Family Services – Medicaid

[www.jfs.ohio.gov/ohp](http://www.jfs.ohio.gov/ohp)

FAQs, eligibility and qualifying information, applications and forms.

Ohio Department of Education – Students with Disabilities

[www.ode.state.oh.us/GD/Templates/Pages/ODE/ODEPrimary.aspx?Page=2&TopicRelationID=967](http://www.ode.state.oh.us/GD/Templates/Pages/ODE/ODEPrimary.aspx?Page=2&TopicRelationID=967)

Information and links to Ohio's programs for students with disabilities.

Healthy Start Healthy Families

[www.jfs.ohio.gov/OHP/consumers/familychild.stm](http://www.jfs.ohio.gov/OHP/consumers/familychild.stm)

Ohio's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Ohio Department of Mental Retardation & Developmental Disabilities

[www.mrdd.ohio.gov](http://www.mrdd.ohio.gov)

Portal for obtaining services for persons with disabilities.

Ohio Department of Health – Bureau for Children with Medical Handicaps

[www.odh.ohio.gov/odhprograms/cmh/cwmh/bcmh1.aspx](http://www.odh.ohio.gov/odhprograms/cmh/cwmh/bcmh1.aspx)

State run network of healthcare providers for children with medical handicaps and programs to pay for services. Services administered through DOH offices in each county.

Ohio Department of Mental Health

[www.mh.state.oh.us](http://www.mh.state.oh.us)

Links to local mental health services.

Ohio Legal Rights Service

<http://olrs.ohio.gov>

Advocacy and referrals for persons with disabilities who are having difficulties obtaining special education services and disability benefits.

### ***Community Resources***

Assistive Technology of Ohio

[www.atohio.org](http://www.atohio.org)

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

Memorial Inc.

[www.memorialinc.org](http://www.memorialinc.org)

Educational and advocacy services for families of children with disabilities in the Cincinnati area.

The Ohio Coalition for the Education of Children with Disabilities (OCECD)

<http://www.oecd.org/oecd/about/index.cfm>

Assistance for parents of children with disabilities in navigating special education programs. Parent to parent mentoring, trainings and conferences offered.

Special Education Services (SES)

<http://www.idealaw.org/Welcome.html>

No cost legal advocacy in the area of special education for income eligible families. Assistance with IEP development, attendance at meetings, referrals to available community services.

Tools for Today and Tomorrow

<http://www.toolsfortoday.org>

Information and support for parents of children with disabilities in or near Cuyahoga County.

## OKLAHOMA

### *State Agencies*

#### Oklahoma Healthcare Authority – Sooner Care (Medicaid and CHIP)

<http://www.okhca.org>

Enrollment and eligibility requirements for Oklahoma's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid and Oklahoma's Medicaid.

#### Oklahoma State Department of Education: Special Education Services

[www.sde.state.ok.us/Curriculum/SpecEd/Resources\\_Parents.html](http://www.sde.state.ok.us/Curriculum/SpecEd/Resources_Parents.html)

Resources for parents of children utilizing Oklahoma's Special Education programs.

#### Oklahoma Department of Human Services – Programs and Services for Persons with Disabilities

[www.okdhs.org/programsandservices/docs/disabilities.htm](http://www.okdhs.org/programsandservices/docs/disabilities.htm)

Entry point for services for persons with disabilities including SSI and TEFRA.

#### Oklahoma Department of Mental Health and Substance Abuse Services

[www.odmhsas.org](http://www.odmhsas.org)

Information and links to mental health services and hotlines.

#### Oklahoma Office of Disability Concerns – Client Assistance Program

[www.odc.ok.gov/cap.html](http://www.odc.ok.gov/cap.html)

Assistance for individuals with disabilities to obtain and maintain employment.

#### Oklahoma Statewide Community Resource Directory

[www.join.ok.gov](http://www.join.ok.gov)

Directory of services and programs available through the Oklahoma state government. Includes an eligibility questionnaire.

### *Community Resources*

#### Oklahoma ABLE Tech

<http://okabletech.okstate.edu>

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

#### Oklahoma Disability Law Center, Inc.

[www.oklahomadisabilitylaw.org](http://www.oklahomadisabilitylaw.org)

Legal advocacy and assistance in obtaining special education services.

#### Oklahoma Family Network

<http://www.oklahomafamilynetwork.org/ofn>

Oklahoma's statewide parent to parent mentorship and resource referral network that assists parents in obtaining special education services for their child with disabilities.

#### Oklahoma Parent Training and Information Center (PTI)

[www.oklahomaparentscenter.org/About.html](http://www.oklahomaparentscenter.org/About.html)

Parent Training and Information Center assisting parents of children with disabilities in obtaining special education services.

## OREGON

### *State Agencies*

#### Oregon Health Plan – Medicaid and SCHIP

[www.oregon.gov/DHS/healthplan/app\\_benefits/main.shtml](http://www.oregon.gov/DHS/healthplan/app_benefits/main.shtml)

Enrollment and eligibility requirements for Medicaid and the Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### Oregon Office of Learning Partnerships – Special Education

<http://www.ode.state.or.us/search/results/?id=40>

Information and links to Oregon’s programs for students with disabilities.

#### Oregon Department of Human Services – Supports for Children with Developmental Disabilities

[www.oregon.gov/DHS/dd/children/overview.shtml](http://www.oregon.gov/DHS/dd/children/overview.shtml)

Information about services for children with developmental disabilities. Eligibility determined through local Community Developmental Disabilities Programs (CDDP). Link to local office locator.

#### Child and Adolescent Mental Health Services

[www.oregon.gov/DHS/mentalhealth/index.shtml](http://www.oregon.gov/DHS/mentalhealth/index.shtml)

Mental health services portal with links to children’s services, publications and crisis services.

### *Community Resources*

#### Access Technologies, Inc.

[www.accesstechnologiesinc.org](http://www.accesstechnologiesinc.org)

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

#### Oregon Advocacy Center

[www.oradvocacy.org](http://www.oradvocacy.org)

Assistance, legal advocacy and information about obtaining special education programs and disability benefits.

#### Oregon Families Information Referral Services and Training (Oregon FIRST)

<http://www.orfirst.org>

Community Parent Resource Center serving Washington, Multnomah and Clackamas Counties.

#### The Oregon Parent Training and Information Center

<http://www.orpti.org>

Parent Training and Information Center assisting parents of children with disabilities in obtaining special education services.

## PENNSYLVANIA

### *State Agencies*

#### **Pennsylvania Department of Health and Human Services – COMPASS**

[www.dpw.state.pa.us](http://www.dpw.state.pa.us)

Online application for state benefits and services including Medicaid, CHIP, and Home and Community-based Services for persons with disabilities.

#### **Pennsylvania Department of Public Welfare – Office of Medical Assistance Programs – Medicaid**

[www.dpw.state.pa.us/ServicesPrograms/MedicalAssistance](http://www.dpw.state.pa.us/ServicesPrograms/MedicalAssistance)

FAQs, eligibility and qualifying information, applications and forms. Local County Assistance Office locator provided.

#### **Pennsylvania Department of Education: Special Education**

[http://www.pde.state.pa.us/special\\_edu/site/default.asp](http://www.pde.state.pa.us/special_edu/site/default.asp)

Information and links to Pennsylvania's programs for students with disabilities.

#### **Pennsylvania's Children's Health Insurance Program**

<http://chipcoverspakids.com>

Pennsylvania's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Pennsylvania Department of Public Welfare – Services for Persons with Disabilities**

[www.dpw.state.pa.us/ServicesPrograms/PhysicalDisabilities](http://www.dpw.state.pa.us/ServicesPrograms/PhysicalDisabilities)

Links to state programs for persons with disabilities. Local County Assistance Office locator provided.

#### **Pennsylvania Department of Public Welfare – Mental Health Services**

<http://www.dpw.state.pa.us/ServicesPrograms/MentalHealthSubstanceAbuse/003676642.htm>

Link to a county Mental Health/Mental Retardation office locator.

### *Community Resources*

#### **Disability Rights Network of Pennsylvania**

[www.drnpa.org](http://www.drnpa.org)

Information and advocacy for individuals with disabilities to access special education programs and disability benefits.

#### **Hispanos Unidos para Ninos Excepcionales (Philadelphia HUNE, Inc.)**

<http://huneinc.org>

Free bilingual (English and Spanish) training, technical assistance and individual assistance to parents of infants, toddlers, children, and youth with disabilities.

#### **The Mentor Parent Program, Inc.**

[www.mentorparent.org](http://www.mentorparent.org)

Support for parents of children with disabilities in Northwest Pennsylvania. Parent to parent mentoring in special education issues.

#### **Parent Education Advocacy Leadership Center**

<http://www.pealcenter.org>

Parent Training and Information Center assisting parents of children with disabilities to obtain special education services. Parent to Parent mentoring, advocacy and training.

#### **P.E.N. – Parent Education Network**

<http://www.parentednet.org>

Parent Training and Information Centers (PTIs), serving Philadelphia, North Central, South Central, Northeast, and Southeast Pennsylvania.

#### **Parent to Parent of Pennsylvania**

[www.parenttoparent.org](http://www.parenttoparent.org)

Parent to parent mentoring for families of children and adults with disabilities.



**Pennsylvania Client Assistance Program**

[www.equalemployment.org](http://www.equalemployment.org)

Assistance to individuals with disabilities to obtain and maintain employment.

**Pennsylvania's Initiative on Assistive Technology**

<http://disabilities.temple.edu>

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

## PUERTO RICO

### *State Agencies*

Estado Libre Asociado de Puerto Rico – Departamento de Salud – Medicaid  
[www.salud.gov.pr/Programas/ProgramaMedicaid/Pages/default.aspx](http://www.salud.gov.pr/Programas/ProgramaMedicaid/Pages/default.aspx)  
FAQs, eligibility and qualifying information, applications and forms.

Servicios a Niños con Necesidades Especiales de Salud  
[www.salud.gov.pr/programas/programamadresninosadolescentes/Pages/default.aspx](http://www.salud.gov.pr/programas/programamadresninosadolescentes/Pages/default.aspx)  
Services for children with neurological problems through multidisciplinary Pediatric Centers. List of local centers and contact information.

Departamento de Educación – Secretaría Asociada de Educación Especial  
[www.de.gobierno.pr/dePortal/Nuestro%20Departamento/Oficina%20del%20Secretario/SASEPI/SASEPI.aspx](http://www.de.gobierno.pr/dePortal/Nuestro%20Departamento/Oficina%20del%20Secretario/SASEPI/SASEPI.aspx)

Overview of Puerto Rico’s Special Education programs, including FAQs and parents’ rights.

Oficina Del Procurador De Las Personas Con Impedimentos  
[www.oppi.gobierno.pr](http://www.oppi.gobierno.pr)

Assistance, legal advocacy and information to obtain special education programs and disability benefits.

### *Community Resources*

Asociación de Padres Pro Bienestar de Niños con Impedidos de Puerto Rico, Inc. (APNI, Inc.)  
[www.apnipr.org](http://www.apnipr.org)

Parent Training and Information Center assisting parents of children with disabilities in obtaining special education services. Parent to Parent mentoring, advocacy and training.

## RHODE ISLAND

### *State Agencies*

**Department of Health Services – Medical Assistance Program – Medicaid and RIticaid**  
[www.dhs.state.ri.us/dhs/adults/dmadult.htm](http://www.dhs.state.ri.us/dhs/adults/dmadult.htm)

Enrollment and eligibility requirements for Medicaid and RIticaid, Rhode Island's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**State Department of Education: Office of Special Populations**  
[www.ride.ri.gov/Special\\_Populations/Default.aspx](http://www.ride.ri.gov/Special_Populations/Default.aspx)

Information and links to Rhode Island's programs for students with disabilities.

#### **RIt Care**

[www.dhs.state.ri.us/dhs/famchild/shcare.htm](http://www.dhs.state.ri.us/dhs/famchild/shcare.htm)

Rhode Island's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**Rhode Island Department of Health – Office of Special Healthcare Needs**  
[www.health.ri.gov/family/specialneeds/resources.php](http://www.health.ri.gov/family/specialneeds/resources.php)

Information for parents on adolescent healthcare transition and other topics.

**Rhode Island Department of Human Services – CEDARR Family Centers**  
[www.dhs.state.ri.us/dhs/dcedarr.htm](http://www.dhs.state.ri.us/dhs/dcedarr.htm)

CEDARR Family Centers (Comprehensive Evaluation, Diagnosis, Referral and Re-evaluation) offer families information and referrals to community support and assistance for their child with special needs.

**Rhode Island Department of Human Services – Children with Special Needs**  
[www.dhs.state.ri.us/dhs/famchild/dchspec.htm](http://www.dhs.state.ri.us/dhs/famchild/dchspec.htm)

FAQs and information about services for children with special needs, including CEDARR Family Resource Centers and the Katie Beckett medical waiver program.

### *Community Resources*

**Family to Family of Rhode Island**  
[www.rifamilytofamily.net](http://www.rifamilytofamily.net)

Information, resources and support from other families of children with disabilities.

**Family Voices of the Rhode Island Parent Information Network**  
[www.ripin.org](http://www.ripin.org)

Parent Training and Information Center assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

**Parent Support Network of Rhode Island**  
[www.psnri.org](http://www.psnri.org)

Organization for parents of children and youth with serious behavioral, emotional, and/or mental health challenges.

## SOUTH CAROLINA

### *State Agencies*

#### South Carolina Department of Health and Human Services – Medicaid

[www.dhhs.state.sc.us/dhhsnew/beneficiaries.asp](http://www.dhhs.state.sc.us/dhhsnew/beneficiaries.asp)

Information about South Carolina's Medicaid program. FAQs, eligibility and qualifying information, applications and forms.

#### South Carolina Department of Education: Special Education

<http://ed.sc.gov/topics/educationsupportsvcs/ec>

Information about South Carolina's Special Education programs.

#### Healthy Connections Kids (SCHIP)

<http://www.dhhs.state.sc.us/dhhsnew/InsideDHHS/Bureaus/BureauofEligibilityProcessing/phc.asp?ProgramID=Benif>

South Carolina's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### South Carolina Client Assistance Program

[www.govoepp.state.sc.us/cap](http://www.govoepp.state.sc.us/cap)

Assistance to individuals with disabilities to obtain and maintain employment.

#### The South Carolina Department of Disabilities and Special Needs (DDSN)

[www.ddsn.sc.gov/consumersandfamilies/default.htm](http://www.ddsn.sc.gov/consumersandfamilies/default.htm)

Information about services for South Carolinians with severe, lifelong disabilities. Includes Medicaid Waiver services.

#### South Carolina Department of Health and Environmental Control – Children's Rehabilitative Services

[www.scdhec.gov/health/mch/cshcn/programs/crs/index.htm](http://www.scdhec.gov/health/mch/cshcn/programs/crs/index.htm)

Statewide network of children's medical services, social work services, nutrition services, parent-to-parent support, physical, occupational and speech therapies, delivered at 8 Regional Public Health Office sites around the state.

#### South Carolina Department of Mental Health

[www.state.sc.us/dmh/services.htm](http://www.state.sc.us/dmh/services.htm)

Links to the state's mental health services and facilities.

### *Community Resources*

#### Family Resource Center for Disabilities and Special Needs, Inc.

[www.frcdsn.org](http://www.frcdsn.org)

Support, training, information and referrals to families accessing special education services for their children and youth with disabilities in Charleston and throughout the Low Country.

#### PRO Parents

<http://www.proparents.org>

Parents Reaching Out to Parents (PRO) is a Parent Training and Information Center for families of children with special needs.

#### Protection and Advocacy for People with Disabilities, Inc.

[www.protectionandadvocacy-sc.org](http://www.protectionandadvocacy-sc.org)

Information and resources to assist parents of children with disabilities in self-advocating for special education services and disability benefits. Investigates reports of school restraint and seclusion.

#### South Carolina Assistive Technology Program

[www.sc.edu/scatp](http://www.sc.edu/scatp)

Assistance in obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment recycling programs.

## SOUTH DAKOTA

### *State Agencies*

#### **South Dakota Department of Social Services – Medicaid and CHIP**

[www.dss.sd.gov/medicaleligibility](http://www.dss.sd.gov/medicaleligibility)

Enrollment and eligibility requirements for Medicaid and South Dakota's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid. Link to Disabled Children's Programs.

#### **South Dakota Department of Education – Special Education Programs**

[www.doe.sd.gov/oess/specialed/Family/index.asp](http://www.doe.sd.gov/oess/specialed/Family/index.asp)

Information for parents about South Dakota's Special Education services.

#### **South Dakota Department of Human Services – Division of Developmental Disabilities**

[www.dhs.sd.gov/dd](http://www.dhs.sd.gov/dd)

FAQs and links to programs and services for persons with developmental disabilities. Includes link to Disability Determination Services which includes information about expediting an SSI claim.

#### **Department of Human Services – Division of Mental Health**

<http://dhs.sd.gov/dmh>

Mental health services for children and adults provided through community mental health centers. Includes crisis intervention services and medication management.

#### **Department of Human Services – Respite Care Program**

[www.dhs.sd.gov/dd/resp/resp/index.aspx](http://www.dhs.sd.gov/dd/resp/resp/index.aspx)

Respite care program which pays for providers to care for children or adults with special needs while the caretakers take a class, go to a movie, go on vacation, or enjoy any activity. Respite care is available to eligible families regardless of income.

### *Community Resources*

#### **South Dakota Advocacy Services**

[www.sdadvocacy.com](http://www.sdadvocacy.com)

Information and advocacy for individuals with disabilities to obtain special education services and disability benefits.

#### **South Dakota Cares**

[www.southdakotacares.org](http://www.southdakotacares.org)

Access to assistive technology and medical equipment through the Recycle for Life program.

#### **South Dakota Parent Connection, Inc.**

<http://www.sdparent.org/whoweare.html>

Parent Training and Information Center assisting parents of children with disabilities to obtain special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

#### **South Dakota Parent Information and Resource Center**

[www.sdpirc.org](http://www.sdpirc.org)

Parent Information and Resource Center assisting parents with support, training, information and referrals to special education services for their children and youth with disabilities.

## TENNESSEE

### *State Agencies*

#### State of Tennessee TennCare – Medicare

[www.state.tn.us/tenncare](http://www.state.tn.us/tenncare)

Information about Tennessee’s Medicaid program. Enrollment and eligibility requirements.

#### Tennessee Department of Education, Division of Special Education

[www.state.tn.us/education/speced](http://www.state.tn.us/education/speced)

Information about Tennessee’s Special Education services.

#### TENnderCARE

[www.tn.gov/tenncare/tenndercare/index.html](http://www.tn.gov/tenncare/tenndercare/index.html)

Tennessee’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

### *Community Resources*

#### Disability Law & Advocacy Center of Tennessee (DLAC)

[www.dlactn.org](http://www.dlactn.org)

Information and advocacy for individuals with disabilities in accessing special education programs and disability benefits. Online self-advocacy information library.

#### Disability Pathfinder

[www.kc.vanderbilt.edu/tnpathfinder](http://www.kc.vanderbilt.edu/tnpathfinder)

Database of disability services and resources available in each Tennessee county. Telephone or email assistance navigating disability services. Developed by the John F. Kennedy Center for Research on Human Development at Vanderbilt University and the Council on Developmental Disabilities.

#### Support and Training for the Exceptional Parent

[www.tnstep.org](http://www.tnstep.org)

Information, parent advocacy training, and support services to parents of children eligible to receive special education services.

## TEXAS

### ***State Agencies***

**Texas Health and Human Services Commission – Healthcare Coverage: Children and Youth**  
[www.hhsc.state.tx.us/Medicaid/index.html](http://www.hhsc.state.tx.us/Medicaid/index.html)

Enrollment and eligibility requirements for Children’s Medicaid and Texas’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**State Department of Education: Special Education**  
<http://ritter.tea.state.tx.us/special.ed>

Information about Special Education services. Includes links to parent’s rights documents, mediation services, the Texas Assistive Technology Network and more.

**TexCare**  
[www.texcarepartnership.com/CHIP-CHIP-Page.htm](http://www.texcarepartnership.com/CHIP-CHIP-Page.htm)

Texas’s Children’s Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

**Texas Department of State Health Services – Children with Special Healthcare Needs (CSHCN) Services Program**  
[www.dshs.state.tx.us/cshcn](http://www.dshs.state.tx.us/cshcn)

Medical services for children who have exhausted all available Medicaid, CHIP and commercial health insurance benefits. Quick Link to Client Handbook.

**Texas Department of Assistive and Rehabilitative Services – Disability Determination Services**  
<http://www.dars.state.tx.us/services/dds.shtml>

FAQs on Disability Determinations for Texans who apply for Social Security Disability Insurance and/or Supplemental Security Income. Applications are made at a local Social Security Office.

### ***Community Resources***

**Advocacy, Inc.**  
[www.advocacyinc.org](http://www.advocacyinc.org)

Technical assistance by private attorneys representing students with disabilities, development and dissemination of written materials for parents on a variety of education issues, and parent training on special education issues.

**CDIC – Community Parent Resource Center**  
[www.cdicelpaso.org](http://www.cdicelpaso.org)

Community Parent Resource Center in El Paso offering information, parent advocacy training, and support services to parents of children eligible to receive special education services.

**PATH Project**  
[www.partnerstx.org](http://www.partnerstx.org)

Parent Training and Information Center (PTI) serving Dallas, Fort Worth, Austin, Wichita Falls, Southeast and East Texas, assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

**Partners Resource Network (PRN)**  
[www.partnerstx.org](http://www.partnerstx.org)

Partners Resource Network (PRN) is a non-profit agency that operates the statewide network of federally funded Parent Training and Information Centers (PTI’s) in Texas, assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

**PEN Project**  
[www.partnerstx.org](http://www.partnerstx.org)

Parent Training and Information Center (PTI) serving Amarillo, Lubbock, Abilene, San Angelo, and El Paso, assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

**Special Kids, Inc. (SKI)**  
[www.specialkidsinc.org](http://www.specialkidsinc.org)

Information, parent advocacy training, and support services to parents of children eligible to receive special education services in the Houston area. One on one consultations, support groups and parent trainings.

**Team Project**  
[www.partnerstx.org](http://www.partnerstx.org)

Parent Training and Information Center (PTI) serving San Antonio, Houston, and the Lower Rio Grande Valley, assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

**Texas Parent to Parent**  
[www.txp2p.org](http://www.txp2p.org)

Information, parent advocacy training, and support services to parents of children eligible to receive special education services in the Austin/Rio Grande Valley areas. Parent to parent peer support, support groups and parent trainings.

**Texas Project First**  
[www.texasprojectfirst.org](http://www.texasprojectfirst.org)

Special education project of the Texas Education Agency, which provides accurate and consistent information and resources to students with disabilities and their families.



## UTAH

### ***State Agencies***

#### **Utah Department of Health – Utah Medicaid Program**

[www.health.utah.gov/medicaid](http://www.health.utah.gov/medicaid)

Information about Utah's Medicaid program. Enrollment and eligibility requirements.

#### **Utah Department of Education: Special Education**

<http://www.schools.utah.gov/sars>

Information on Utah's Special Education services.

#### **Utah CHIP**

[www.utahchip.org](http://www.utahchip.org)

Utah's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Utah Department of Human Services – Division of Services for People with Disabilities**

<http://www.dspd.utah.gov>

Home and community-based services for persons with disabilities, including community living, day services, supported employment services, and support for people with disabilities and their families. Program and Services links offers overviews and applications for services.

#### **Utah Department of Health – Community & Family Health Services (CFHS)**

<http://health.utah.gov/cfhs/aboutus.html>

Information about services for children with special healthcare needs. Includes Medicaid Waiver programs.

#### **Utah Center for Assistive Technology**

[www.usor.utah.gov:81/ucat](http://www.usor.utah.gov:81/ucat)

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

### ***Community Resources***

#### **Access Utah Network (Statewide Information and Referral for Disability Issues)**

[www.accessut.org](http://www.accessut.org)

Information and referral for individuals with disabilities. Telephone disability helpline and links to assistive equipment for sale.

#### **Disability Law Center**

[www.disabilitylawcenter.org](http://www.disabilitylawcenter.org)

Information and advocacy for individuals with disabilities in accessing special education programs and disability benefits.

#### **The Medical Home Portal**

[www.medicalhomeportal.org/?redirectDomain=true](http://www.medicalhomeportal.org/?redirectDomain=true)

Assisting parents of children with disabilities to become effective partners in their care with physicians and other healthcare professionals.

#### **Utah Parent Center (UPC)**

<http://www.utahparentcenter.org>

Parent Training and Information Center (PTI) assisting parents of children with disabilities in obtaining special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

## VERMONT

### ***State Agencies***

#### **Vermont Green Mountain Care**

[www.greenmountaincare.org](http://www.greenmountaincare.org)

FAQs, information and application for programs such as Dr. Dynasaur (Vermont's Children's Health Insurance Program – CHIP), Vermont Health Access Plan (VHAP), and Medicaid, as well as the new Catamount Health. Low-cost and free health coverage programs for uninsured Vermonters.

#### **Vermont Department of Education: Student Support Services – Parental Resources**

[www.education.vermont.gov/new/html/pgm\\_sped/parents.html](http://www.education.vermont.gov/new/html/pgm_sped/parents.html)

Provides information, resources and support to parents, guardians and families of children with disabilities.

#### **Vermont Division of Disability and Aging Services – Department of Disabilities, Aging and Independent Living**

[www.ddas.vermont.gov](http://www.ddas.vermont.gov)

Community-based long-term care services for individuals with developmental disabilities and physical disabilities. Includes Children's Personal Care Services, Developmental Disability Services and the Choices for Care long-term care and Medicaid Waiver programs.

#### **Vermont Agency of Human Services – Department of Disabilities, Aging and Independent Living – Vermont Assistive Technology Project**

[www.dail.state.vt.us/ATP](http://www.dail.state.vt.us/ATP)

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

#### **Vermont Department of Health – Children with Special Health Needs (CSHN)**

[www.healthvermont.gov/family/cshn/cshn.aspx](http://www.healthvermont.gov/family/cshn/cshn.aspx)

Information about state programs and services for children with complex medical conditions.

#### **Vermont Department of Mental Health – Agency of Human Services**

<http://mentalhealth.vermont.gov/cafu>

FAQs and information on Vermont's mental health programs for children and youth.

### ***Community Resources***

#### **Disability Law Project**

[www.vtlegalaid.org](http://www.vtlegalaid.org)

Legal assistance for parents of children with disabilities to obtain special education services and disability benefits.

#### **Parent-to-Parent of Vermont**

[www.partoparvt.org](http://www.partoparvt.org)

Medicaid and SSI consulting. Parent to parent mentoring programs.

#### **Vermont Family Network**

[www.vermontfamilynetwork.org](http://www.vermontfamilynetwork.org)

Information and resources to assist parents of children with disabilities, ages birth thru 26 years, to effectively participate in their children's education, development, and transition to adult life.

#### **Vermont Protection and Advocacy, Inc.**

[www.vtpa.org](http://www.vtpa.org)

Assistance with obtaining special education services and disability benefits.

## VIRGINIA

### ***State Agencies***

#### **Virginia Department of Medical Assistance Services – Medicaid**

[www.dmas.virginia.gov/rcp-home.htm](http://www.dmas.virginia.gov/rcp-home.htm)

FAQs and documents about Virginia's Medicaid program, long term care and Waiver services, including eligibility for children under age 19.

#### **Virginia Department of Education: Division of Special Education – Parent Resources**

[www.doe.virginia.gov/VDOE/sped/parents.shtml](http://www.doe.virginia.gov/VDOE/sped/parents.shtml)

FAQs and information for parents of children using special education services.

#### **FAMIS**

[www.famis.org](http://www.famis.org)

Virginia's Children's Health Insurance program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services – How to Get Help**

[www.dbhds.virginia.gov/SVC-default.htm](http://www.dbhds.virginia.gov/SVC-default.htm)

FAQs about programs for persons with developmental disabilities in Virginia. Link to Community Services Boards, which are portals to services.

#### **Virginia Department of Health – Children with Special Healthcare Needs – Care Connection for Children (CCC)**

[www.vahealth.org/specialchildren/ccsprogram.asp](http://www.vahealth.org/specialchildren/ccsprogram.asp)

Specialty medical services and medical insurance benefits evaluation for children with chronic health problems. Eligibility requirements and a map of service areas and CCC offices.

### ***Community Resources***

#### **Medical Home Plus**

[www.medhomeplus.org](http://www.medhomeplus.org)

Organization offering an online Family Resource Center, Resource Referrals by phone, and Service Coordination to obtain special education services.

#### **Parent Educational Advocacy Training Center (PEATC)**

<http://www.peatc.org>

Parent Training and Information Center assisting parents of children with disabilities with information and support to obtain special education services.

#### **Parent to Parent of Virginia**

<http://www.ptpofva.com>

Programs to assist parents of children with disabilities to obtain special education services and disability benefits. Parent to Parent mentoring, advocacy and training.

#### **Virginia Assistive Technology System (VATS)**

[www.vats.org/aboutvats.htm](http://www.vats.org/aboutvats.htm)

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

## WASHINGTON

### *State Agencies*

Washington Department of Health and Social Services – Health and Recovery Services Administration – Medicaid

[www.adsa.dshs.wa.gov/pubinfo/benefits/medicaid.htm](http://www.adsa.dshs.wa.gov/pubinfo/benefits/medicaid.htm)

Information about Washington's Medicaid program. Enrollment and eligibility requirements.

State of Washington – Office of Superintendent of Public Instruction – Special Education

[www.k12.wa.us/specialed](http://www.k12.wa.us/specialed)

Information about Washington's Special Education programs. Link to assessment information, dispute resolution, etc. Link to citizen's representative – the Ombudsman.

Children's Health Insurance Program (SCHIP)

<http://hrsa.dshs.wa.gov/CHIP/Index.html>

Washington's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

Washington Department of Health and Social Services – Division of Developmental Disabilities (DDD)

[www.dshs.wa.gov/ddd](http://www.dshs.wa.gov/ddd)

Central information hub for DDD services, assessment procedures and waiver programs. Links to Washington's mental health programs.

Washington Client Assistance Program

[www.washingtoncap.org](http://www.washingtoncap.org)

Assistance for persons with disabilities who wish to work or continue working.

### *Community Resources*

Families Together

[www.familiestogether.org](http://www.familiestogether.org)

Rural outreach serving Southeast Washington for families of children with disabilities. Support and information on advocacy for parents and nondisabled siblings.

Parent to Parent Power

<http://p2ppower.org>

Organization assisting Asian parents of children with disabilities to obtain special education services and disability benefits.

PROVAIL

[www.provail.org](http://www.provail.org)

66 year-old organization that offers therapeutic and assistive technology services, dental clinic, employment services and employment opportunities in their Fabrication Division.

University of Washington School of Dentistry: Referral Services

[www.dental.washington.edu/disability](http://www.dental.washington.edu/disability)

Quick locator of dental resources for persons with disabilities.

Washington Assistive Technology Act Program

[www.watap.org](http://www.watap.org)

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

Washington PAVE

[www.washingtonpave.org](http://www.washingtonpave.org)

Parent Training and Information Center (PTI) offering resources, training and support for parents of children with disabilities. Parent to parent mentoring.

## WEST VIRGINIA

### *State Agencies*

West Virginia Department of Health and Human Resources – Bureau for Children and Families – Medicaid

[www.wvdhhr.org/bms](http://www.wvdhhr.org/bms)

Information about West Virginia's Medicaid program. Online application. County office locator.

West Virginia Department of Education – Special Education – Parent Educator Resource Center  
<http://wvde.state.wv.us/osp/perc.html>

Information for parents about West Virginia's Special Education programs. Link to Parent Guide.

West Virginia CHIP

[www.wvchip.org](http://www.wvchip.org)

West Virginia's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

West Virginia Bureau for Behavioral Health and Health Facilities – Division for Developmental Disabilities

[www.wvdhhr.org/bhhf/mrdd.asp](http://www.wvdhhr.org/bhhf/mrdd.asp)

Information about West Virginia's programs for persons with developmental disabilities and their families including the Family Support program and Mental Health Crisis Services.

### *Community Resources*

West Virginia Advocates

[www.wvadvocates.org](http://www.wvadvocates.org)

Information to assist parents of children with disabilities in obtaining special education services, assistive technology and disability benefits.

West Virginia Parent Training and Information Project (WVPTI)

[www.wvpti.org](http://www.wvpti.org)

Parent Training and Information Center (PTI) offering resources, training and support for parents of children with disabilities to obtain special education services and disability benefits. Parent to parent mentoring.

## WISCONSIN

### ***State Agencies***

#### **Wisconsin Department of Health Services – Medicaid**

[www.dhs.wisconsin.gov/medicaid](http://www.dhs.wisconsin.gov/medicaid)

Information about Wisconsin's Medicaid program. Online enrollment forms and eligibility requirements.

#### **Wisconsin State Department of Education: Special Education**

[www.dpi.wi.gov/sped/hmparents.html](http://www.dpi.wi.gov/sped/hmparents.html)

Information for parents of children accessing Wisconsin's Special Education programs.

#### **Wisconsin Department of Health Services – BadgerCare+**

[www.dhs.wisconsin.gov/BadgerCarePlus](http://www.dhs.wisconsin.gov/BadgerCarePlus)

Wisconsin's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Wisconsin Department of Health Services – Children and Youth with Special Healthcare Needs Program**

<http://dhs.wisconsin.gov/health/children>

Services, including Medical Home Care, for children with chronic health conditions. Link to Wisconsin First Step searchable service database for children and youth with disabilities.

#### **Wisconsin Department of Health Services – Wisconsin's Assistive Technology (WisTech) Program**

<http://dhs.wisconsin.gov/disabilities/wistech/index.htm>

Assistance obtaining assistive technology for persons with disabilities through training and demonstrations, equipment loans, financial loans and used equipment programs.

#### **Wisconsin Department of Vocational Rehabilitation – Client Assistance Program**

[www.wicap.wisconsin.gov/index.jsp](http://www.wicap.wisconsin.gov/index.jsp)

Assistance for persons with disabilities to obtain and maintain employment.

### ***Community Resources***

#### **Family Voices of Wisconsin**

[www.wfv.org/fv](http://www.wfv.org/fv)

Family Voices provides information, training and support around healthcare and community services for families and professional partners.

#### **MUMS – National Parent to Parent Network**

[www.netnet.net/mums](http://www.netnet.net/mums)

Parent to parent support and mentoring program. Maintains a database to match parents by age, geographical local, gender and severity of the child's disability.

#### **Parent to Parent of Wisconsin**

[www.p2pwi.org](http://www.p2pwi.org)

Parent to parent mentoring in the areas of special education services, healthcare and community services. Links to other organizations and resources.

#### **Wisconsin Family Assistance Center for Education, Training and Support (FACETS)**

[www.wifacets.org](http://www.wifacets.org)

Parent Training and Information Center (PTI) offering resources, training and support for parents of children with disabilities in obtaining special education services and disability benefits. Parent to parent mentoring.

## WYOMING

### ***State Agencies***

#### **Wyoming Department of Health – Equality Care (Medicaid)**

<http://wdh.state.wy.us/healthcarefin/medicaid/eligibility.html>

Eligibility and application information about EqualityCare, Wyoming's Medicaid program. Downloadable Healthcare Coverage Application, which is also used for Kid Care CHIP. Link to District map of the Department of Family Services offices where applications are submitted.

#### **Wyoming Department of Education – Special Education**

[www.k12.wy.us/se.asp](http://www.k12.wy.us/se.asp)

General information about Wyoming's Special Education programs. Downloadable IEP and Dispute Resolution forms.

#### **KidCare CHIP**

<http://wdh.state.wy.us/healthcarefin/chip/index.html>

Wyoming's Children's Health Insurance Program (CHIP) which offers affordable health insurance for children and teens not eligible for Medicaid.

#### **Wyoming Department of Health – Mental Health and Substance Abuse – Children's Waiver Program**

[www.health.wyo.gov/mhsa/treatment/waiverindex.html](http://www.health.wyo.gov/mhsa/treatment/waiverindex.html)

Program for treating severe mental illness in a child or teen in their home communities with their parents/families involved in all aspects of their treatment.

#### **Wyoming Department of Health – Children's Special Healthcare Program**

<http://wdh.state.wy.us/familyhealth/csh/index.html>

Downloadable brochure about Wyoming's program for children with chronic health problems. Provides care coordination and support services.

### ***Community Resources***

#### **Parent Education Network (PEN)**

[www.wpen.net](http://www.wpen.net)

Parent Training and Information Center (PTI) offering resources, training and support for parents of children with disabilities to obtain special education services and disability benefits. Parent to parent mentoring.

#### **Parent Information Center**

[www.wpic.org](http://www.wpic.org)

Workshops and trainings for parents of children with disabilities for self advocacy in the area of special education.

#### **Rehabilitation Enterprises of North Eastern Wyoming (RENEW)**

[www.renew-wyo.com](http://www.renew-wyo.com)

Assistance with a variety of supported employment opportunities for persons with disabilities.

#### **Wyoming Protection and Advocacy System, Inc.**

[www.wyopanda.com/programs.asp](http://www.wyopanda.com/programs.asp)

Advocacy and assistance in obtaining special education and other services.

## HDSA Resource Section

A Guide to HDSA's Chapters, Affiliates, Regions and Centers of Excellence

HDSA has placed professional staff in strategic locations across the country to provide assistance in fund raising, awareness, education and care initiatives offered by HDSA in support of HDSA's mission.

Regional Development Directors are responsible for the states listed including all chapters, affiliates and HDSA Centers of Excellence within that region. Regional Development Directors work directly with HDSA volunteers to maximize local resources and efforts in the care and cure of HD.

Information changes constantly. Please contact HDSA at 800-345-HDSA for updated information or go to the HDSA national web site at [www.hdsa.org](http://www.hdsa.org) and click on "Find HDSA in your Community."

### HDSA National Field Development and Operations Director

Nancy Rhodes  
HDSA National Office  
Tel: 212-242-1968 or 800-345-4372

### HDSA National Field Development and Operations Manager

Alex Roque  
HDSA National Office  
Tel: 212-242-1968 ext. 223  
Email: aroque@hdsa.org

### NEW ENGLAND REGION

*(CT, ME, MA, NH, RI, VT)*  
Virginia Goolkasian  
HDSA Regional Development Director  
Tel: 978-256-0811 or (toll free) 888-554-8102  
Email: vgoolkasian@hdsa.org

### HDSA Chapters

*Connecticut Affiliate*  
c/o Susan McGann  
Tel: 860-558-8847  
Email: smcgann@hdsa-ct.org

*Maine Affiliate*  
c/o Raima Fernald  
Tel: 207-283-4945  
Email: raimajeane@yahoo.com

*New Hampshire Affiliate*  
c/o Charlene Weed  
Tel: 603-742-1348  
Email: weedswd@comcast.net

*Massachusetts Chapter*  
c/o Virginia Goolkasian  
HDSA Regional Development Director  
[www.hdsa-ne.org](http://www.hdsa-ne.org)

### GREATER NEW YORK REGION

*(NY, NJ, Fairfield County, CT)*  
Chenell Tannure  
HDSA Regional Special Events Coordinator  
Tel: 212-242-1968 ext. 221  
Email: ctannure@hdsa.org

### HDSA Chapters

*Long Island Affiliate*  
*New York Metro Affiliate*  
c/o Chenell Tannure

*New Jersey Chapter*  
c/o Christi Kobus Rokicki  
Executive Director  
Tel: 973-784-4965  
[www.hdsanj.com](http://www.hdsanj.com)  
crokicki@hdsa.org

*Upstate New York Chapter*  
c/o Chenell Tannure  
HDSA Regional Special Events Coordinator  
212-242-1968 ext.221  
[www.hdsaunyo.org](http://www.hdsaunyo.org)

### MID-ATLANTIC REGION

*(DE, PA, WVA, VA, MD, Wash DC)*  
c/o HDSA National Field Development and Operations Department  
Tel: 212-242-1968 or (toll free) 800-345-4372



## HDSA Chapters

*Delaware Valley Chapter*  
c/o Susan Liberace  
HDSA Chapter Executive Director  
Tel: 610-260-0420  
Email: sliberace@hdsa.org  
www.dvhdsa.org

*Delaware Chapter*  
Tel: 877-384-3721

*Washington Metro Chapter*  
Tel: 703-204-4634  
703-323-1403  
http://www.dchdsa.org

*Western Pennsylvania Chapter*  
Tel: 412-833-8180  
888-779-HDSA (4372)  
www.hdsawpa.org

## SOUTHEAST REGION

*(NC, SC, AL, GA, FL)*  
HDSA National Field Development and Operations  
Department  
Tel: 212-242-1968 or (toll free) 800-345-4372

## HDSA Chapters

*North Carolina Chapter*  
c/o Worth Bolton  
Tel: 919-389-9224  
www.hdsanc.org

*Georgia Chapter*  
Tel: 404-223-2294  
www.hdsa-ga.org

*Central Florida Affiliate*  
c/o Karen Milek  
Tel: 407-719-2291

*South Florida Chapter*  
Tel: 305-274-7411  
www.huntingtonsdiseasefl.org

## GREAT LAKES REGION

*(MI, IN, OH, KY, WI, MO (St. Louis only))*  
c/o HDSA National Field Development and  
Operations Department  
Tel: 212-242-1968 or (toll free) (800-345-4372)

## HDSA Chapters

*Central Ohio Chapter*  
c/o Wendy Vaughan  
Tel: 614-460-8800  
866-877-HDSA (4372)  
Email: wvaughan@hdsa.org  
http://www.hdsacentralohio.org

*Indiana Chapter*  
Tel: 317-271-0624 or (toll free) 866-488-0008  
www.hdsaindiana.org

*Kentucky Chapter*  
Tel: 502-637-4372  
800-784-3721 (KY only)  
Email: hdsakychapter@bellsouth.net

*Michigan Chapter*  
Tel: 989-832-4170  
800-909-0073  
Email: hdsami@att.net  
http://hdsa-mi.com

*Northeast Ohio Chapter*  
c/o Barbara Kaiser  
Tel: 330-998-6600  
Email: Bkaiser@hdsa.org

*Ohio Valley Chapter*  
Tel: 513-741-HSDA (4372)

*St. Louis Chapter*  
c/o Peggy Cribbin  
HDSA Chapter Executive Director  
Tel: 314-647-HSDA (4372)  
866-707-4372  
Email: pcribbin@hdsa.org  
www.hdsastl.org

*Wisconsin Chapter*  
Tel: 414-257-9499  
877-330-2699  
www.hdsawi.org

## SOUTHWEST REGION

*(TX, OK, LA, MS, AR, KS, TN, MO (except St. Louis))*  
Janice Watsky  
HDSA Regional Development Director  
Tel: 504-712-0523 or 866-712-0523  
Email: jwatsky@hdsa.org

## HDSA Chapters

### *Oklahoma Chapter*

Tel: 405-236-4372 or 877-232-4372

www.okhdsa.com

okhdsa@sbcglobal.net

### *Arkansas Affiliate*

Tel: 800-558-3370

800-536-1728 (pin no. 5935)

hdsa-arkansas@comcast.net

### *Texas Affiliate*

Tel: 504-712-0523

www.hdsatexas.org

## UPPER MIDWEST REGION

(ND, SD, NE, MN, IA, IL)

Leigh Peterson

HDSA Regional Development Director

Tel: 763-502-1407

Email: lpeterson@hdsa.org

## HDSA Chapters

### *Illinois Chapter*

Tel: 630-443-9876

www.hdsa-il.com

### *Iowa Chapter*

Tel: 866-248-4243

712-542-4976

Email: mail@hdsaiowa.org

### *Minnesota Chapter*

Tel: 612-371-0904

Email: hdsamn@hdsa.org

www.hdsa-mn.org

### *Sioux Valley Chapter*

Tel: 605-334-9917

## ROCKY MOUNTAIN REGION

(NM, UT, WY, AZ, CO)

Kendell Aitchison

HDSA Regional Development Director

Tel: (303) 837-9937

E-mail: kaitchison@hdsa.org or  
regional@hdsarockymountain.org

### *Rocky Mountain Chapter*

c/o Kendell Aitchison

HDSA Regional Development Director

Tel: 303-321-5503 or 877-740-4372

www.hdsarockymountain.org

## NORTHWEST REGION

(WA, OR, ID, MT)

HDSA National Field Development and  
Operations Department

Tel: 212-242-1968 or (toll free) 800-345-4372

## HDSA Chapters

### *Northwest Chapter*

c/o Roxanne Harris

HDSA Special Events Coordinator

Tel: 206-464-9598

Email: nwhdsa@yahoo.com

www.nwhdsa.org

## NORTHERN CALIFORNIA REGION

(No. CA, NV)

Penny Riley

HDSA Regional Development Director

Tel: 916-927-4400

Email: priley@hdsa.org

## HDSA Chapters

### *Northern California Chapter*

c/o Penny Riley

HDSA Regional Development Director

Tel: 916-927-4400 or 888-828-7344

Email: priley@hdsa.org

www.hdsanortherncalifornia.org

## SOUTHERN CALIFORNIA REGION

(So. CA, S. NV)

c/o Natalie Carpenter

Tel: 619-225-2255

Email: ncarpenter@hdsa.org

## HDSA Chapters:

### *Greater Los Angeles Chapter*

Tel: 888-4-HDSA LA

800-686-9868

### *Orange County Chapter*

Tel: 866-920-0601

www.hdsaoc.org

### *San Diego Chapter*

Tel: 800-473-4014

619-225-2255

www.hdsasandiego.org

## HDSA SOCIAL WORKERS

HDSA social workers are located at all 21 HDSA Centers of Excellence and 17 HDSA Chapters. The list below is offered for informational purposes only.

Inclusion does not constitute an endorsement or recommendation by HDSA. Information changes constantly. Please visit the HDSA national web site for the most up to date contact information.

### ALABAMA

*HDSA Center of Excellence at the  
HD Clinic at the Children's Hospital of Alabama*  
Birmingham, AL  
Social Worker: Lynda Williams, MSW, LGSW  
Tel: 205-939-9085  
Email: lynda.williams@chsys.org

### ARIZONA

*Arizona Affiliate*  
Tempe, AZ 85282  
Social Worker: Christina Bates, MC, LPC  
Tel: 480-200-8595  
Email: christinabates@cox.net

*Arizona Affiliate*  
Tucson, AZ  
Social Worker: Joan Jervis, LPC  
Tel: 520-886-6063  
Email: joanjervis@comcast.net

### CALIFORNIA

*HDSA Center of Excellence at University of California  
Davis Medical Center*  
Social Worker: Corey Lucero-Perkins  
Tel: 916-734-6277  
Email: coreen.lucero-perkins@ucdmc.ucdavis.edu

*HDSA Center of Excellence at University of  
California*  
San Diego, CA  
Social Worker: Lisa Snyder, MSW, LCSW  
Tel: 858-622-5800  
Email: lsnyder@ucsd.edu

*HDSA Center of Excellence at UCLA*  
Los Angeles, CA  
Social Worker: Barbara Fallick, MSW  
Tel: 310-794-1225  
Email: BGF4231942@yahoo.com

### CONNECTICUT

*University of Connecticut Health Center  
Huntington's Disease Program*  
Farmington, CT  
Social Worker: Bonnie Hennig, MSW, LCSW  
Tel: 860-679-4441  
Email: hennig@psychiatry.uchc.edu

### COLORADO

*Center of Excellence at the Colorado Neurological  
Institute*  
Engelwood, CO  
Tel: 720-974-4092

*Rocky Mountain Chapter*  
Wheat Ridge, CO  
Social Worker: Jan Jerome, LCSW  
Tel: 720-371-5806  
Email: socialworker@hdsarockymountain.org

### DELAWARE

*Delaware Valley Chapter*  
Plymouth, PA  
Social Worker: Joanne Luz  
Tel: 877-384-3721  
Email: jluz@dvhdsa.org

### FLORIDA

*HDSA Center of Excellence at the University of  
South Florida*  
Tampa, FL  
Social Worker: Lisa Bentivenga, MSW  
Phone: 813-974-6022  
Email: lbentive@health.usf.edu

### GEORGIA

*HDSA Center of Excellence at Emory School of  
Medicine*  
Atlanta, GA  
Social Worker: Lynn Ross, LMSW  
Tel: 404-728-6300  
Email: slross@emory.edu

### ILLINOIS

*HDSA Center of Excellence at Rush University  
Medical Center*  
Chicago, IL  
Social Worker: Marjorie Johnson, MSW, MFT  
Tel: 312-563-2900  
Email: Marjorie\_G\_Johnson@rush.edu

### INDIANA

*Chapter & Indiana University HDSA Center of  
Excellence*  
Indiana University School of Medicine  
Indianapolis, IN  
Social Worker: Leo Rafail, BSW  
Tel: 866-488-0008  
Email: info@hdsaindiana.org

## IOWA

*HDSA Center of Excellence at University of Iowa  
Hospitals and Clinics*  
Iowa City, IA  
Social Worker: Anne Leserman, MSW, LISW  
Tel: 319-353-4307  
Email: anne-leserman@uiowa.edu

## KENTUCKY

*Kentucky Chapter*  
Louisville, KY  
Social Worker: Cathy Saliga, LCSW  
Tel: 502-637-4372  
Email: hdsakychapter@bellsouth.net

## MARYLAND

*HDSA Center of Excellence at Johns Hopkins*  
Baltimore, MD  
Social Worker: Catherine McFarlane, MSW  
Tel: 410-955-2497  
Email: cmcfar1@jhmi.edu

## MASSACHUSETTS

*Chapter & New England HDSA Center of  
Excellence*  
Charlestown, MA  
Social Worker: Judith Sinsheimer, LCSW  
Tel: 617-726-2603  
Email: jsinsheimer@partners.org  
*New England Social Worker*  
Social Worker: Eric St. Onge, MSW  
Tel: 888-554-8102 ext. 12  
Email: estonge@hdsa.org

## MICHIGAN

*Michigan Chapter*  
Dimondale, MI  
Social Worker: Danny Berry, LBSW  
Tel: 800-909-0073  
Email: hdsamisw@gmail.com

## MINNESOTA

*Minnesota Chapter*  
Social Worker: Jessica Hancock, LSW  
Tel: 612-371-0904 or 877-371-0904  
Email: jhancoc1@good-sam.com  
*Center of Excellence at Hennepin County Medical  
Center*  
Minneapolis, MN  
Social Worker: Nina Ross, LISW  
Tel: 612-873-3369  
Email: Nina.Ross@hcmed.org

## MISSOURI

*Chapter & HDSA Center of Excellence at  
Washington University School of Medicine*  
St. Louis, MO  
Social Worker: Stacey Barton, LCSW, MSW  
Tel: 314-362-3471  
Email: bartons@neuro.wustl.edu

## NEW JERSEY

*Huntington's Disease Family Service Center*  
Piscataway, NJ  
Social Worker: Christine Hogan, LCSW  
Tel: 732-235-5993  
Email: hoganch1@umdnj.edu

*Center for Aging*  
Stratford, NJ  
Social Worker: Nancy M. Alterman, LCSW  
Tel: 856-566-7078  
Email: altermnm@umdnj.edu

## NEW YORK

*HDSA Center of Excellence at Columbia Health  
Sciences/ New York State Psychiatric Institute*  
New York, NY  
Social Worker: Debbie Thorne, LCSW  
Tel: 212-305-9172  
Email: thorned@sergievsky.cpmc.columbia.edu

*George C. Powell HDSA Center of Excellence at  
North Shore University Hospital*  
Great Neck, NY  
Social Worker: Patricia Lambert, LCSW  
Tel: 631-234-0136  
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*HDSA Center of Excellence at University of  
Rochester*  
Rochester, NY  
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## OHIO

*HDSA Center of Excellence at Ohio State University*  
Columbus, OH  
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*Ohio Chapter*  
Cincinnati, OH  
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Email: howardb33@aol.com

*Northeast Ohio Chapter*  
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Email: kitzmiller27kr@yahoo.com

## PENNSYLVANIA

*Delaware Valley Chapter*  
Plymouth, PA  
Social Worker: Joanne Luz  
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*Western Pennsylvania Chapter*  
Pittsburgh, PA  
Social Worker: Peggy Polito, MSW  
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## SOUTH DAKOTA

*Sioux Valley Chapter*  
Sioux Falls, SD  
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## TEXAS

*HDSA Center of Excellence at Baylor College of Medicine*  
Houston, TX  
Social Worker: Alicia Palao, MA  
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Email: palao@bcm.tmc.edu

*Texas Chapter*  
Dallas, TX  
Social Worker: Cheryl Lenheiser, LCSW  
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## VIRGINIA

*HDSA Center of Excellence at University of Virginia*  
Charlottesville, VA  
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## WASHINGTON

HDSA Center of Excellence at University of Washington  
Seattle, WA  
Social Worker: Donna Ross, MSW, LICSW  
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## WISCONSIN

*Wisconsin Chapter*  
Wauwatosa, WI  
Social Worker: Jean Morack, ACSW, MSW  
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## HDSA Resource Directory

HDSA Centers of Excellence program serves as the cornerstone of HDSA's commitment to care. These 21 facilities provide a vast array of medical and social services to HD families nationwide and work in collaboration with HDSA chapters, affiliates, regions and support groups to form a seamless national network of resources and referrals for those affected by HD and their families.

HDSA Centers of Excellence also offer family members the opportunity to be a part of the search for effective treatments and a cure through clinical trials. As research advances, there will be a greater need for individuals who want to be a part of finding the answers. To find out more about clinical trials in your area, please visit the Huntington Study Group at [www.huntington-study-group.org](http://www.huntington-study-group.org).

Each HDSA Center of Excellence receives an annual grant of \$50,000 from HDSA which is used to support patient and family service programs. These annual grants are funded through special events organized by HDSA chapters, regions, volunteers and friends who recognize the important role that these Centers of Excellence play in providing help to our families. To find out more about fund raising events in your area, please visit the HDSA web site at [www.hdsa.org](http://www.hdsa.org) and click on "Community".

### NEW ENGLAND

**New England HDSA Center of Excellence**  
Charlestown, MA  
Tel: 617-726-5532

### GREATER NEW YORK REGION

**HDSA Center of Excellence at the University of Rochester**  
Rochester, NY  
Tel: 585-273-4147

**HDSA Center of Excellence at Columbia Health Sciences/NYS Psychiatric Institute**  
New York, NY  
Tel: 212-305-9172  
Website: [www.hdny.org](http://www.hdny.org)

**George C. Powell HDSA Center of Excellence at North Shore University Hospital**  
Great Neck, NY  
Tel: 516-570-4477

### MID-ATLANTIC REGION

**HDSA Center of Excellence at Johns Hopkins University/Hospital**  
Baltimore, MD  
Tel: 410-955-2398

**HDSA Center of Excellence at University of Virginia Health System**  
Charlottesville, VA  
Tel: 434-924-2665  
Helpline: 866-290-4528

### SOUTHEAST REGION

**HDSA Center of Excellence at Emory University**  
Atlanta, GA  
Tel: 404-728-6364

**HDSA Center of Excellence at University of Alabama**  
Birmingham, AL  
Tel: 205-996-7865

**HDSA Center of Excellence at University of South Florida**  
Tampa, FL  
Tel: 813-974-6022

### GREAT LAKES REGION

**HDSA Center of Excellence at Ohio State University**  
Columbus, OH  
Tel: 614-688-8672

**HDSA Center of Excellence at Indiana University School of Medicine**  
Indianapolis, IN  
Tel: 866-488-0008

### SOUTH/SOUTHWEST REGION

**HDSA Center of Excellence at Baylor College of Medicine**  
Houston, TX  
Tel: 713-798-3951

### MIDWEST REGION

**HDSA Center of Excellence Washington University School of Medicine**  
St. Louis, MO  
Tel: 314-362-3471  
Website: [www.neuro.wustl.edu/hungtington](http://www.neuro.wustl.edu/hungtington)

## UPPER MIDWEST REGION

**HDSA Center of Excellence at  
Hennepin County Medical Center**  
Minneapolis, MN  
Tel: 612-873-2595 (new appointments)  
Tel: 612-873-2515 (appointments)  
Tel: 612-873-2522 (nurse line for established  
patients)

**HDSA Center of Excellence at  
University of Iowa Hospitals and Clinics**  
Iowa City, IA  
Tel: 319-353-4307  
Web site: [www.uihealthcare.com/depts/  
huntingtonsdisease](http://www.uihealthcare.com/depts/huntingtonsdisease)

**HDSA Center of Excellence at  
Rush University Medical Center**  
Chicago, IL  
Tel: 312-563-2900

## ROCKY MOUNTAIN REGION

**HDSA Center of Excellence at  
Colorado Neurological Institute**  
Englewood, CO  
Tel: 303-768-4600

## NORTHWEST REGION

**HDSA Center of Excellence at  
University of Washington**  
Seattle, WA  
Tel: 206-598-4030

## NORTHERN CALIFORNIA REGION

**HDSA Center of Excellence at  
University of California  
Davis Medical Center**  
Sacramento, CA  
Tel: 916-734-6278

## SOUTHERN CALIFORNIA REGION

**HDSA Center of Excellence at  
University of California, Los Angeles**  
Los Angeles, CA  
Tel: 310-794-1225

**HDSA Center of Excellence at  
University of California, San Diego**  
San Diego, CA  
Tel: 858-622-5824